

Palliative Care and End-of-Life Care

Opportunities for the
NHS Ten Year Plan

June 2025, Volume 2

Commission on Palliative
and End-of-Life Care

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Chapter One: Overview

Evidence

As part of its evidence-gathering process, the Commission issued a public call for written submissions, receiving a total of 532 responses. These submissions were collected via an online platform and free-text, categorised by contributor type: 295 from clinicians, commissioners, and service providers; 151 from patients, families, and carers; 77 from academics and researchers; and 9 from respondents who did not specify a category. The call was widely disseminated through professional networks, academic institutions, voluntary organisations, hospices, and social media channels to ensure diverse and representative input.

The online questionnaire included a combination of closed and open-ended questions. All respondents were asked to describe their role or perspective, and to provide insights on several key areas including:

- What is working well in palliative care and end-of-life care
- Major barriers or challenges
- Suggestions for improvement
- Experiences of accessing or delivering care
- Issues related to equity, integration, and communication

In addition, respondents were asked specific questions based on their experiences. For example, academic and clinical contributors were also asked to provide evidence-based reflections or data relevant to their practice or research. In addition, family members and carers were invited to share personal experiences of care provision and outcomes.

Submissions were analysed using a qualitative thematic approach. Common themes were identified through close reading and coding of responses, with patterns tracked across different respondent groups. This approach enabled the Commission to draw out both sector-specific issues and cross-cutting systemic concerns. A total of 96 named organisations were identified through this process, encompassing a wide spectrum of healthcare, academic, charitable, and community-based bodies.

Respondents were also invited to provide additional documentation alongside their written responses. Many did so, including service evaluations, published studies, strategic plans, and audit data. This comprehensive consultation process provided a rich and diverse evidence base for the Commission. The consistency of themes across contributor types and settings lends weight to the recommendations outlined in Volume 1, including the need for systemic change, policy reform, and investment in integrated, equitable palliative and end-of-life care across the UK.

Recurring themes included: fragmented care pathways, inconsistent access to services (particularly in community and out-of-hours settings), significant workforce pressures, variable funding models, and a lack of public understanding and preparedness around end-of-life. These findings provided strong corroborative support for the analysis presented in

Volume 1 of the Commission's report, particularly its recommendations on the need for a coordinated national strategy, workforce development, equitable access, and greater integration between health, social care, and voluntary sectors.

The written evidence process offers a wide-ranging perspective from those working within or directly affected by the palliative and end-of-life care system, forming a critical foundation for the Commission's conclusions and recommendations.

Respondents

The following illustrated the range of 532 respondents:

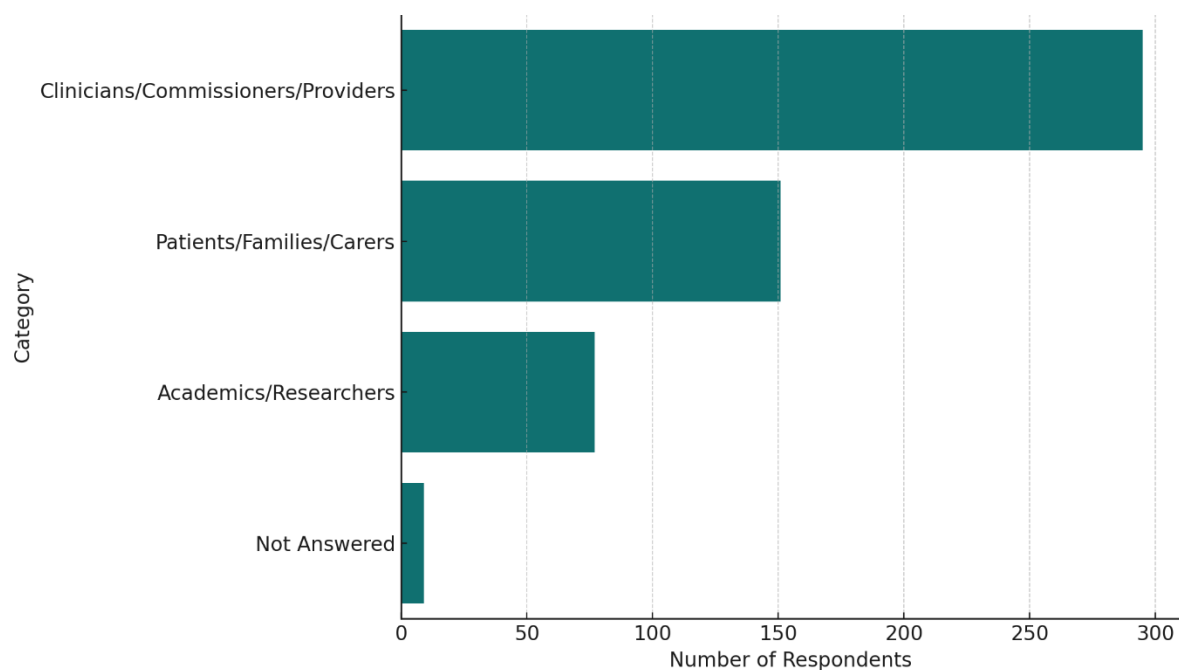


Figure 1 Overall Respondent Categories (n=532)

Clinician/Commissioners/Providers: 295

Patients/Families/Carers: 151

Academics/Researchers: 77

Not answered: 9

Total: 532

Chapter Two: Patients/ Families/ Carers

Breakdown of submissions

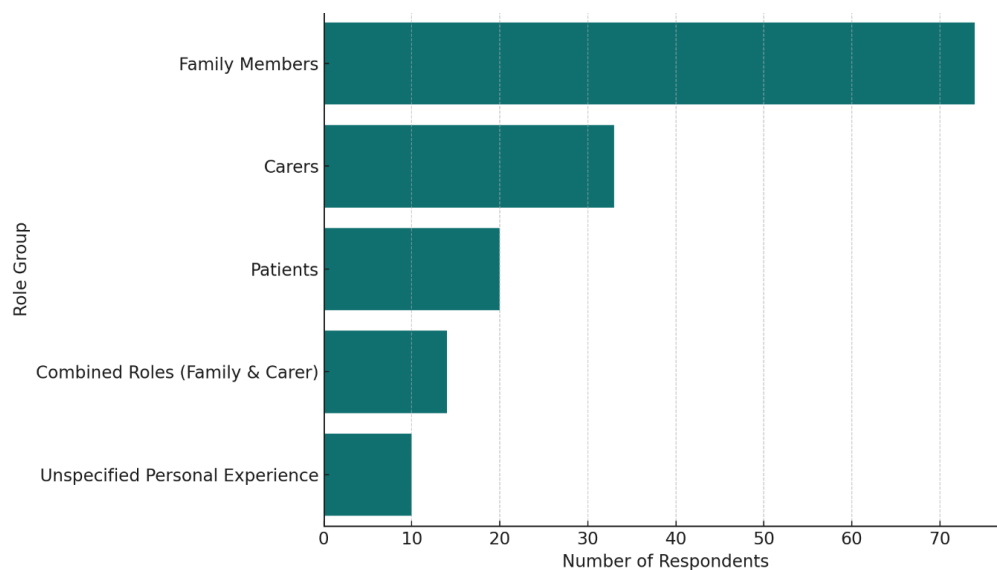


Figure 2 Patients, Families, and Carers Respondents by Role (N=151)

There were a total of 151 free-text submissions from patients, families and carers to the Commission between January and March 2025. The majority of correspondents were family members of patients dealing with terminal illness, or receiving palliative and end-of-life care, either presently or in the past.

74 family members gave extensive accounts of care experiences across hospices, hospitals, and home. Themes include good palliative teams, late referrals, and the emotional toll of poor planning and fragmented care delivery systems:

- 34× Bereaved Relatives
- 21× Parents (including of children and adults)
- 12× Spouses or Partners
- 7× Siblings or Extended Family

Evidence from 33 carers expresses the difficulties navigating systems, need for respite, and gaps in home support or recognition:

- 16× Unpaid Carers (active or recent)
- 9× Former Carers (bereaved, post-support)
- 6× Carers for non-cancer conditions (dementia, COPD, frailty)
- 2× Young or Student Carers

The 20 patients who wrote free-text submissions (currently dealing with terminal illness, or who are receiving/have received palliative care and end-of-life care) expressed the value of

compassionate care, but many encountered challenges in advance planning, control, and choice:

- 9× Individuals currently under palliative care
- 6× People with chronic or life-limiting illness reflecting on past experience
- 5× Patients with complex care needs, multiple admissions, or advanced illness

There were 14 people who were in combined roles, for examples submissions from individuals who are both a family member and unpaid carer. In these submissions, there was a clear overlap of the emotional toll of caring, advocacy for the patient, anticipated grief, and the need to undertake care planning:

- 7× Spouse-Carers (dual role)
- 5× Parent-Carers of children with life-limiting illness
- 2× Carers also receiving care themselves

There were 10 submissions from respondents with unspecified personal experience, describing personal direct or indirect experiences, or providing support to others.

The Value of Palliative Care and End-of-Life Care for those with Lived Experience

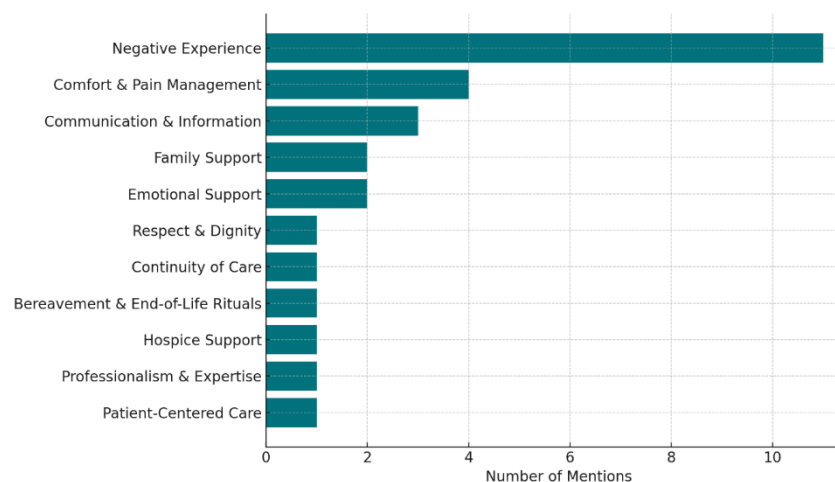


Figure 3 Trends in Valued Aspects of Palliative Care and End-of-Life Care

Respondents were asked ‘What have you valued most about the Palliative Care and End-of-Life Care you/someone you know has been in receipt of?’. Strikingly, while the survey question asked what individuals had valued in their care, several respondents instead described what they had not received or what had gone wrong.

Negative Experience

Negative experiences of general palliative and end-of-life care included the lack of timely action, a sense of dehumanisation and loss of dignity, feeling neglected and isolated, and a failure to acknowledge death. There were gaps in service provision and diagnostic delays. One patient described the lack of timely action-

“Nothing is happening- when you have aggressive cancer... everything comes too late. Your final days are spent queuing for scans”¹

Refocusing on disease prevention rather than only on treatment (one of the ‘three shifts’ from the NHS Ten Year Plan) highlights on the need for timely response to emerging problems, and how this can prevent an illness progressing and worsening over time. The Commission’s report ‘Palliative Care and End-of-Life Care: Opportunities for England (Volume1) stressed the importance of timely identification of palliative care needs.² Evidence of ‘*everything comes too late*’ was a recurring theme in the Commission’s patients roundtables, with repeated accounts of clinicians being reluctant to refer patients to specialist palliative care services early enough, resulting in patients’ problems being poorly addressed and hindering palliative care interventions being maximally effective. Systemic gaps and diagnostic delays were found to be a key player within the lack of timely action. Problems with scans, referrals, and administrative delays led to care being ineffective and hampered.

These comments demonstrated that there had been little adoption of the known evidence that timely action by enhanced supportive care services can improve quality of life, treatment outcomes and overall survival.^{3 4}

The Commission’s recommendation of ‘Improve rapid response to advice and access to community services’ seeks to address the concerns of the lack of timely action.

Comfort and Pain Management

“Making their last months/years comfortable and pain free”⁵

This was expressed as a top priority by family members. Responses from those with lived experience consistently show that alleviating pain and managing symptoms is viewed by patients and families as one of the most essential and appreciated aspects of palliative care.

Respondents also stated that when comfort is prioritised, it made a major difference in how end-of-life care was experienced and remembered. Furthermore, respondents valued symptom improvement through effective pain relief and use of appropriate medications, and were distressed when they witnessed poor pain control.

¹ Patient Written Evidence

² Finlay, I., Richards, M., Maskell, R., et al, Palliative Care and End-of-Life Care: Opportunities for England (Volume 1), The Commission on Palliative and End-of-Life Care, 2025

³ Johnson MJ, Rutterford L, Sunny A, et al, Benefits of specialist palliative care by identifying active ingredients of service composition, structure, and delivery model: A systematic review with meta-analysis and meta-regression. PLoS Med. 2024 Aug 2;21(8):e1004436. doi: 10.1371/journal.pmed.1004436. PMID: 39093900; PMCID: PMC11329153.

⁴ Monnery D, Tredgett K, Hooper D, et al, Delivery Models and Health Economics of Supportive Care Services in England: A Multicentre Analysis. Clin Oncol (R Coll Radiol). 2023 Jun; 35(6):e395-e403. doi: 10.1016/j.clon.2023.03.002. Epub 2023 Mar 11. PMID: 36997458

⁵ Family Member Written Evidence

Communication and Information

Good communication and information-giving was highly valued by those with lived experience. This included open discussion about prognosis and treatment/care options, respectful and open dialogue between patients, families and clinicians. Many felt they were inadequately involved in planning care and had a sense emotional relief when they were involved in decision-making. Relatives called for communication to be improved. Patients appreciated when their wishes were respected and plans were in place ahead of deterioration or a crisis.

There is evidence that discussion of patients' needs and preferences are often being reduced to tick-box exercises.^{6,7}

The Commission's recommendation 'Ensure compassionate, open, and timely communication, supporting future care plans' seeks to ensure positive communication between patients, families and clinicians. The benefits of improved communication and listening to the concerns of the patient and family address key failings in care.⁸ A clear focus on the patient's priorities and wishes restores the patient's sense of control and empowers independence. Moreover, this decreases a sense of being a burden on family, society, and the NHS.²

Support

Support for family was listed among the most valued aspect of care, referring to emotional support both for families facing loss and for patients dealing with a difficult diagnosis. Patients and their families appreciated practical help navigating secondary care systems or care at-home. Clear communication enabled patients and families to understand and express their care wishes. The in-person presence and compassionate approach from staff provided much support.

Notably, 'care' (31%) and 'support' (35%) were expressed as the most valued aspects of palliative care and end-of-life care by patients, families and carers.

The Commission's recommendation 'Support for informal carers and families' addresses the emotional and practical challenges faced carers, accompanied by providing tailored support around dying. Importantly, this protects carers mental health while fostering resilience.²

⁶ Morrison RS, Meier DE, Arnold R.M., Controversies About Advance Care Planning-Reply. *Jama* 2022; 327(7): 686

⁷ Morrison RS, Meier DE, Arnold R.M. What's Wrong with Advance Care Planning? *Jama* 2021; 326(16): 1575-6

⁸ Department of Health, 2013, More care, less pathway. A review of the Liverpool Care Pathway. London.

Improving Palliative Care and End-of-Life Care for those with Lived Experience

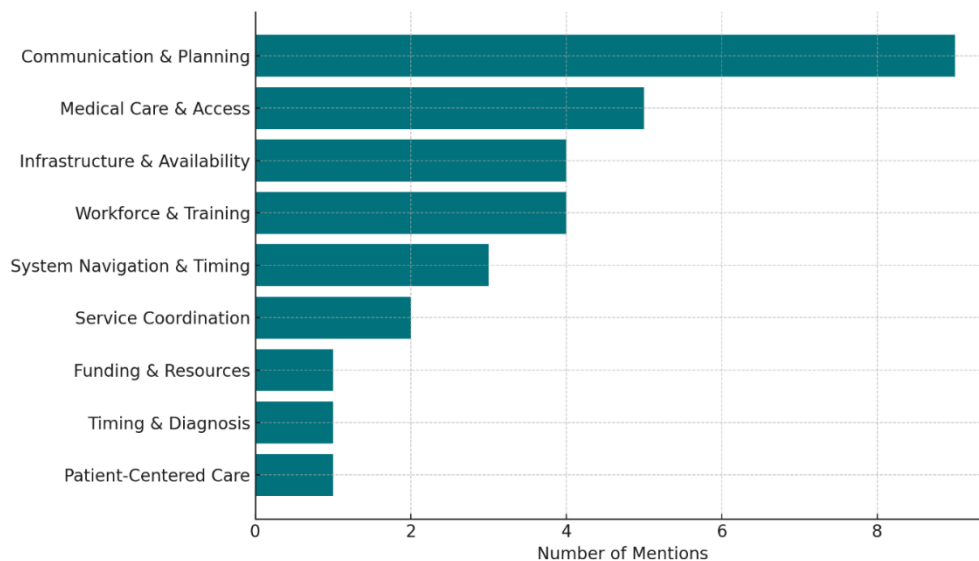


Figure 4 Trends in suggested improvements for palliative care and end-of-life care

Communication and Planning

In response to “What would help the most to improve Palliative and End-of-Life Care?”, many patients, families, and carers identified communication and planning as a top priority for improvement. Respondents described missed opportunities for early, honest conversations about dying and care preferences, which were often delayed until patients were too unwell to participate.

“Recording the patient’s wishes BEFORE they become exhausted and delirious”¹

“Not delaying telling the patient they are dying until they are very physically weak.”¹

“honest communication”⁵

“a better understanding of end of life, death and dying”⁵

“liaise clearly and sympathetically with carers and family”⁵

There was a clear call for compassionate, honest communication from clinicians. This request appeared often, highlighting dissatisfaction with vague or delayed discussions about death. Others stressed the need for professionals to communicate both clearly and sensitively. Families also wanted greater involvement and empathy from clinicians.

These findings support the recommendation that every patient with a life-limiting illness should be given the opportunity to express their wishes and plan future care — in a way that is personalised, regularly reviewed, and supported by clinicians trained in kind and honest communication. Better communication not only improves emotional wellbeing and reduces unnecessary interventions but also builds trust and prevents complaints. It is, as the evidence shows, a cornerstone of quality palliative and end-of-life care.

The Commission's recommendations of 'Ensure compassionate, open and timely communication...' and 'Improve understanding around palliative care, hospices and dying' seek to directly address these improvements.²

Medical Care and Access

Many patients and families highlighted serious gaps in access to medical care. They sought improvements in three main areas: effective symptom relief, timely access to medication, and better community-based clinical support – particularly for those wishing to remain at home. These unmet needs had resulted in avoidable suffering due to slow or uncoordinated care. Respondents pointed to the lack of in-home support and delays in treatment that left patients vulnerable.

*"Drugs, food and water to alleviate her physical pain. The interest of a caring doctor. Caring hospital staff"*⁹

*"Improved domiciliary GP visits"*⁵

*"Timely medication"*⁵

These experiences directly support the Commission's recommendation to improve rapid response and community access, with 24/7 availability of clinical advice, medication, and social care. Strengthening these services would reduce unnecessary hospital admissions, cut costs, and allow more people to remain at home with dignity and comfort.

Infrastructure and Availability

Patients, families, and carers raised concerns about availability and access to services. Respondents pointed to major gaps in hospice facilities, a lack of inpatient beds, and inadequate community support. Many stated the need for more hospices with beds, highlighting the patchy nature of hospice provision, leaving many to struggle to secure appropriate care.

*"Improved community palliative care and home support"*⁵

These experiences support the need to mandate and fund 24/7 specialist palliative care and to ensure coordinated general care in every area (Recommendation 2). This also reinforces the recommendation to develop a National Strategy for palliative and end-of-life care (Recommendation 1), to ensure all regions have the physical and workforce infrastructure needed.²

⁹ Carer's written evidence submission

Workforce and training

The quality of end-of-life care was closely tied to the quality of staff, with concerns raised about gaps in training, empathy, and responsiveness.

“Having the necessary staff to provide such care”⁵

These concerns support the recommendation to improve education and training for all health and social care staff (Recommendation 4), ensuring clinicians can communicate with honesty and kindness, recognise when someone is dying, and manage care confidently. It also backs the need for dual accreditation and recognition of prior experience (Recommendation 5), to expand the palliative care workforce, especially in the community.²

Children as Patients

Submissions relating to children as patients highlight the need for a broader and more inclusive understanding of palliative care for patients of all ages. One detailed account from a parent describes caring for their daughter palliatively throughout her entire 21-year life, challenging narrow definitions that equate palliative care solely with end-of-life. After potentially life-prolonging interventions, such as transplantation, the exclusion of palliative support can be devastating, particularly when the intervention fails to improve quality of life.

“Palliative care... is not limited to end-of-life care. It can, in many instances, be whole life care... That life may be long or it may be short, but how it is cared for is what matters.”⁵

“[She] died in huge amounts of pain over the course of 3 months. This was all because of a protectionist culture from the transplant team.”⁵

“Clinicians empowering patients at the bedside”⁵

This example illustrates how a ‘protectionist culture’ within specialist teams can undermine holistic, multidisciplinary care. Parents also stressed the importance of being listened to and empowered during their child’s care, calling on clinicians to respect a child’s wishes and respecting the parents, as they know the child best. When delivered well, palliative care for children was deeply valued for preserving dignity and providing comfort. These were supportive clinicians who communicated openly and planned care clearly.

Chapter Three: Clinicians/ Commissioners/ Providers

Breakdown of submissions

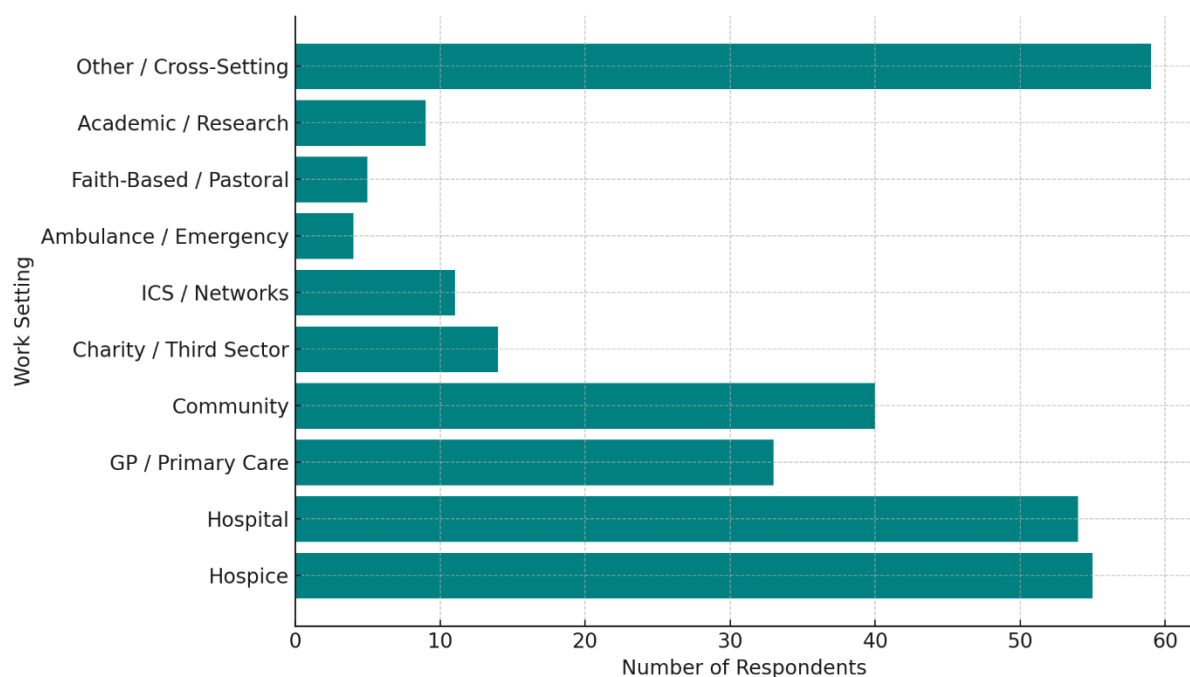


Figure 5 Clinician Respondents by Work Setting (n=295)

There were a total of 295 written submissions from clinicians and care providers to the Commission between January and March 2025. Respondents represented a wide spectrum of roles and settings, from hospices and hospitals to general practice, community services, third sector organisations, and strategic system leadership.

Clinicians working in hospices offered some of the most detailed reflections on holistic, person-centred care and death with dignity:

20× Physicians

24× Nurses

11× Other (including AHPs, Chaplains, Doulas, Volunteers)

Hospital-based clinicians described innovations in identification, escalation, and transitions of care for patients nearing end of life:

24× Physicians

18× Nurses

12× Other (Support Workers, Coordinators, Researchers)

General Practice professionals highlighted the value of long-term continuity, advance care planning, and challenges in community coordination:

13× Physicians (GPs or retired)

9× Nurses
11× Other (Practice Managers, Educators, ANPs)

These included district nursing, local authority teams, and social care providers. Themes focused on proactive outreach, inequalities, and early intervention:

9× Physicians
14× Nurses
17× Other (AHPs, Doulas, Social Workers, Coordinators)

Charity workers and volunteers described deeply compassionate services and financial challenges in sustainability:

2× Physicians
6× Nurses
6× Other (Bereavement Workers, Counsellors, Volunteers)

Strategic leaders outlined workforce gaps, commissioning barriers, and transformation efforts:

5× Physicians
1× Nurse
5× Other (Commissioners, Transformation Leads, Clinical Strategists)

These responses focused on triage, urgent care planning, and difficulties in emergency decision-making:

2× Paramedics
1× Nurse
1× Other (Urgent Care / Triage)

Contributions from retired clinicians and lay pastoral care staff emphasized the spiritual dimensions of dying:

1× Physician (retired GP)
1× Nurse (retired)
3× Other (Volunteers, Lay Pastoral Support, Chaplaincy)

Research professionals and lecturers focused on education, evidence-based care, and evaluation:

2× Physicians
2× Nurses
5× Other (Academics, Research Fellows, Lecturers)

This category reflects a large group of clinicians operating in mixed, ambiguous, or national roles, including policy and voluntary sectors:

21× Physicians

12× Nurses

26× Other (Independent practitioners, Policy Advisors, General contributors)

Proud in Providing Palliative Care and End-of-Life Care

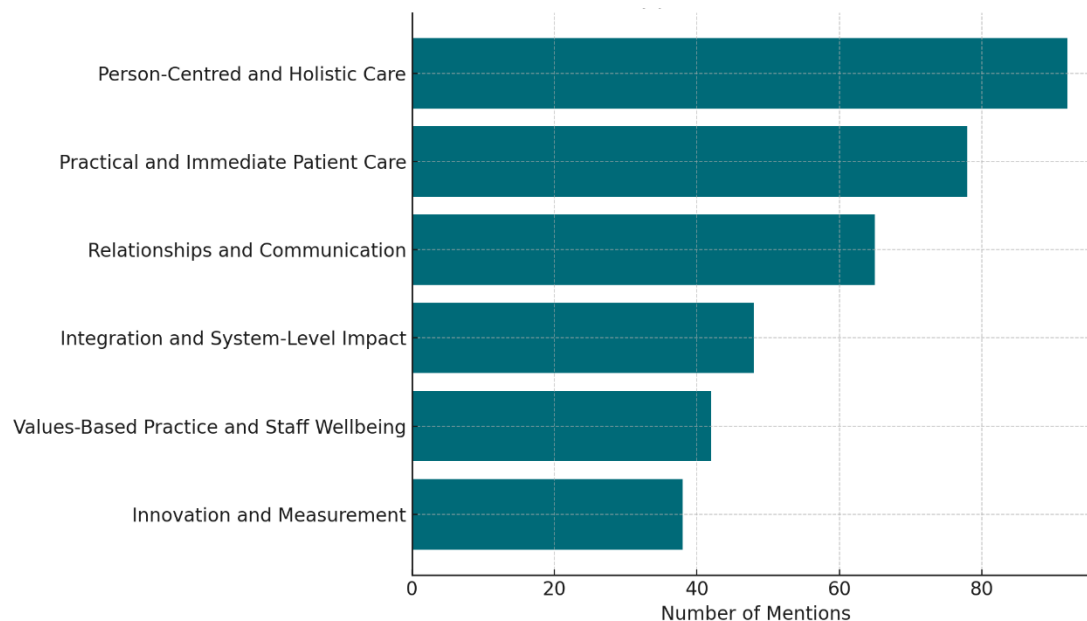


Figure 6 Trends in suggested improvements for palliative care and end-of-life care

Person-Centred and Holistic Care

Clinicians consistently expressed pride in delivering care that is centred around the needs, values, and preferences of each patient- going beyond treating symptoms by respecting a patient's wishes, honouring their autonomy, and creating space for meaning even in the final days.

“Helping support patients at their most vulnerable time of their lives to allow them to die peacefully in their own beds at home.”¹⁰

“Providing quality care for patients and their loved ones. Ensuring that we enable them to live until they die and fulfil their personal goals.”¹¹

These accounts reflect the vision set out in Recommendation 9 of the Commission, which calls for every patient to be given the opportunity to communicate their personal wishes and

¹⁰ Physician written evidence submission

¹¹ Nurse written evidence submission

plan for future care through compassionate, open, and timely conversations. The submissions demonstrate how clinicians are already embedding these principles in practice.

Practical and Immediate Patient Care

Many clinicians found pride in delivering the immediate, often unseen care that brings comfort and dignity to patients at the end of life. This includes managing pain, supporting mobility and nutrition, and helping people to remain at home where they feel most secure.

“Helping people to feel better – enabling a patient to be able to walk by controlling their pain, enabling a patient to eat by exploring why they thought they couldn’t.”¹⁰

“As a service being able to provide the highest possible care to patients in their own homes so that they can be cared for and allowed to die were they wish.”¹¹

These practical interventions are directly supported by Recommendations 2 and 3 of the Commission, which mandate 24/7 access to specialist palliative care and call for a rapid response to community needs, including equipment, medication, and support. Clinicians’ pride in these areas reflects their commitment to reducing hospital admissions and crises while improving patient comfort and autonomy.

Relationships and Communication

A strong theme across submissions was the value clinicians placed on their relationships with patients and families. Many described being present during the most emotionally charged and meaningful moments of a person's life.

“Sitting with families and dying people in the last few weeks and hours of life.”¹⁰

“Using Clean Language questions can enable rapid clarity, focus on desired outcomes, whilst minimising unhelpful assumptions.”¹⁰

These stories align closely with Recommendation 4, which highlights the need for comprehensive education and training so that all staff feel confident having honest, kind, and skilled conversations. They also support Recommendation 9, which stresses that future care plans should be developed through timely, compassionate dialogue. Clinicians are already doing this emotional work—and take justified pride in it.

Barriers to delivering optimal palliative and end-of-life care

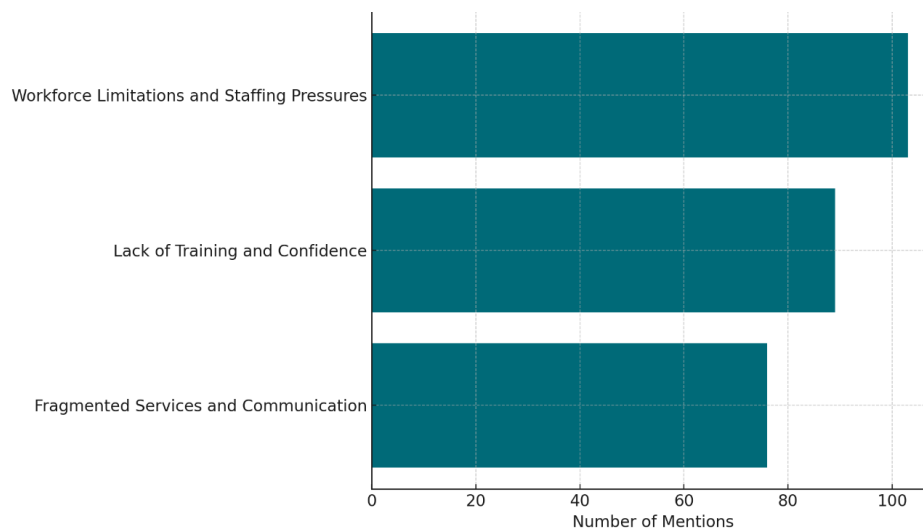


Figure 7 Top Barriers to Delivering Optimal Palliative Care and End-of-Life Care

“There is inequity in access to good quality palliative and end-of-life care. Different commissioning arrangements and many services being provided on goodwill leads to a postcode lottery, meaning not all families can access services they may need. Funding is often short-term and charitable, which doesn’t provide stability, sustainability, or reliability. It also means staff often aren’t sure what families could access based on their postcode, which is important knowledge in sensitive conversations. There is also age inequity, as services available for adults may not be available for BCYP, such as 24/7 face-to-face nursing care at home at end-of-life.”¹²

Workforce Limitations and Staffing Pressures

A major and consistent concern across the 295 clinician submissions was the significant strain on the palliative care workforce. Clinicians highlighted the widespread shortage of skilled staff and the impact this has on service delivery and staff wellbeing.

“Lack of adequately trained staff”¹³

“Insufficient trained palliative care staff in the community.”¹⁴

“Many services being provided on goodwill leads to a postcode lottery.”¹²

“Risk of staff burnt-out increasing sickness absence and high turnover rates.”¹⁵

¹² MDT clinicians (paediatric) written evidence submission

¹³ Psychologist written evidence submission

¹⁴ Clinician written evidence submission

¹⁵ Provider written evidence submission

These challenges are directly addressed by Recommendation 1, which calls for the development of a National Strategy for palliative care and end-of-life care. This strategy must include workforce planning for both generalist and specialist care, with annual Ministerial accountability. In addition, Recommendation 5 supports the introduction of dual accreditation in specialist palliative medicine for those training in general practice, and the recognition of prior experience, helping to retain skilled professionals and facilitate movement into palliative care roles.

Lack of Training and Confidence in Palliative Care Delivery

Clinicians repeatedly identified the lack of adequate training as a major barrier to delivering high-quality palliative care and end-of-life care. Several submissions noted that professionals lack the confidence and preparation to hold difficult conversations or manage symptoms appropriately. The lack of training undermines the ability to provide truly holistic and anticipatory care.

“Hospital staff not trained to recognise a deteriorating or dying patient, therefore those patients aren’t referred to hospital palliative care teams.”¹¹

“Education for carers, GPs and nursing staff.”¹⁰

“Community nurses... need education to see the patient as a whole rather than the task they have to do.”¹¹

Recommendation 4 addresses this issue by calling for education and training for all health and social care staff. It recommends embedding palliative care into undergraduate medical, nursing, and allied health curricula, alongside training modules for those already in practice. This would support professionals in delivering timely, compassionate, and coordinated care, improving outcomes for patients and families.

Fragmented Services and Poor Communication

A third key barrier was the fragmentation of services and poor communication between teams. This often resulted in patients falling through the cracks, duplicate assessments, and inconsistent planning. These systemic disconnects were particularly damaging during out-of-hours care, leading to avoidable hospital admissions and unplanned interventions that contradicted patient preferences.

“Without integrated services, patients experience disjointed care.”¹⁴

“Fragmented healthcare [is] focused on conditions rather than on people and their context.”¹⁰

Recommendation 2 responds to this by calling for the mandating and funding of 24/7 specialist palliative care, working in coordination with generalist care. The recommendation includes a standard that if a patient’s distress is not improving within 48 hours, advice must be sought from a specialist service. Recommendation 3 further proposes expanding rapid response services and improving access to community support, including 24/7 advice lines and evening visiting capacity. These measures would help prevent crises, reduce hospital dependence, and enable joined-up care delivery across all settings.

These top three barriers—workforce shortages, insufficient training, and fragmented care systems—are closely interconnected. The national recommendations address each barrier with targeted, practical solutions aimed at creating a more integrated, resilient, and compassionate model for palliative and end-of-life care.

Improvements to the Service

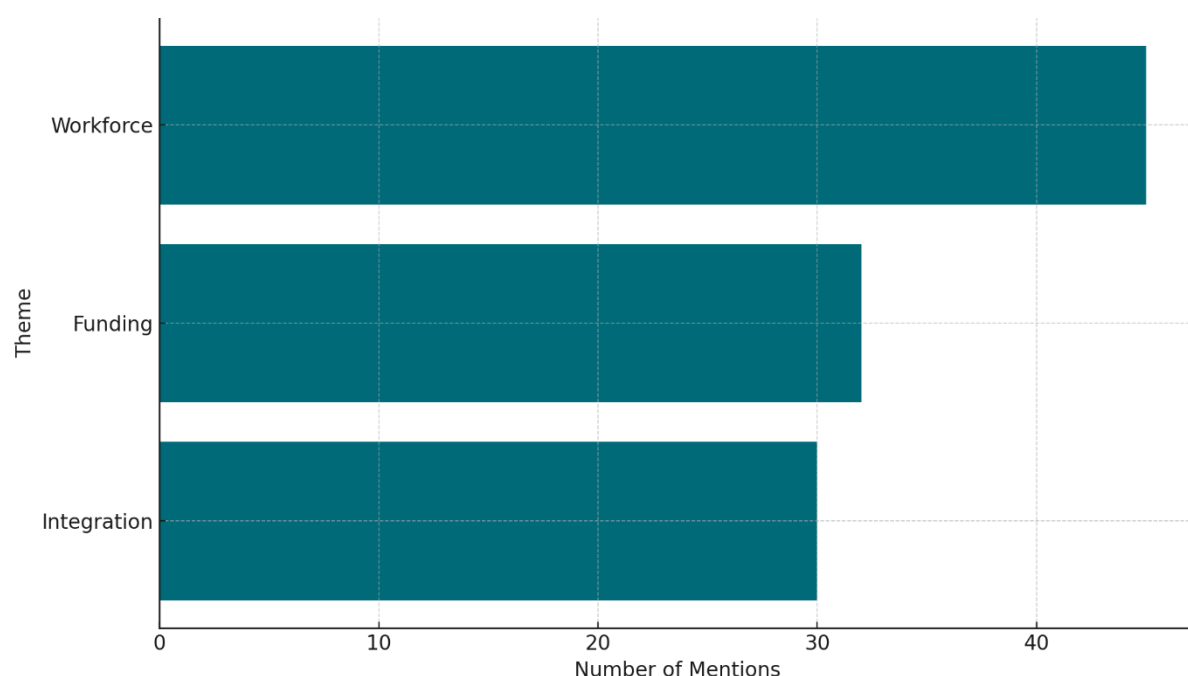


Figure 8 Clinicians' Top Three Improvements to the Service

Workforce Development and Education

The key improvement for palliative care and end-of-life care stated by clinicians is workforce development and education. Clinicians suggested the need to recruit and retain more trained staff, including nurses, doctors, and allied health professionals. Moreover, enhanced education and training for generalist healthcare providers is vital to improve competency in palliative care.

“An integrated programme of workforce development. Embed palliative care in all levels of teaching from student training through to post graduate education across the clinical workforce. Currently the majority of medical students are not taught what dying looks like.

All specialities, from A&E to surgery, should learn about symptom control and how to support dying people and their families. Equally, nurses and AHPs need to be able to identify

what dying looks like too, to enable appropriate care and support to be provided to a patient and their family. This would help address not only the shortage of workforce but also the inappropriate and late referrals and general lack of understanding around palliative care. To address immediate workforce shortages, funds need to be available to pay staff fairly using Agenda for Change.”¹⁶

This aligns with the recommendation to provide education and training for all health and social care staff, making palliative care a core part of undergraduate curricula and offering modules for those already in practice. It also supports the call for dual accreditation and recognition of prior experience, especially for GPs transitioning into specialist roles. These steps will build workforce capacity, improve timely referrals, and support better communication and symptom recognition across all care settings.

Sustainable Funding and Resource Allocation

“Increased funding to improve access for under reached communities.”¹¹

“Invest in Specialist Resources that Reflect Cultural, Emotional, and Practical Needs.”¹⁵

These statements reflect the recommendation to increase sustainable funding for hospices, community services, social care, and voluntary organizations, and to align hospice staff pay with NHS scales. Addressing regional funding disparities and ensuring core clinical services are supported through recurrent NHS funding would reduce the reliance on charitable donations and improve access to equitable, high-quality care. This approach also supports investment in specialist services, such as children’s palliative care, and encourages a shift from acute hospital-based care to community-led models, ensuring that patients receive timely and culturally sensitive support close to home.

Improved Integration, Coordination and Accessibility

“Integrated, contemporaneous and fast IT systems across all providers to aid seamless care and reduce duplication of services and patients having to re-tell their story many times.”¹⁵

This directly supports the recommendation to integrate health and social care data systems, ensuring digital interoperability and seamless communication across providers. Developing shared care pathways, unified electronic patient records, and a single point of access for 24/7 advice and referrals would reduce fragmentation, improve continuity of care, and allow patients and families to avoid repeating their story.

These measures are critical to ensuring coordinated end-of-life care, especially for those wishing to die at home, and would reduce avoidable hospital admissions and inefficiencies in care delivery.

¹⁶ Hospice written evidence submission

Submissions relating to children's palliative care

There were 20 submissions from clinicians who discussed children's palliative care. Many highlighted the need for specialist paediatric services, the need for staff training and confidence, and inequalities of access.

“[The need for] education and awareness of children's palliative care across the healthcare sector: For babies, children and young people to access palliative care appropriately, healthcare professionals need to identify life-limited children who meet the criteria for children's hospice care, and understand the importance of making timely and appropriate referrals. Early interventions can improve overall health outcomes and enhance the quality of life for children with life-limiting conditions. For bereaved families, access to specialist bereavement care plays a crucial role in supporting their mental health, illustrating why a proactive approach and better referral pathways are essential.”¹⁵

Chapter Four: Academics

Breakdown of Submissions

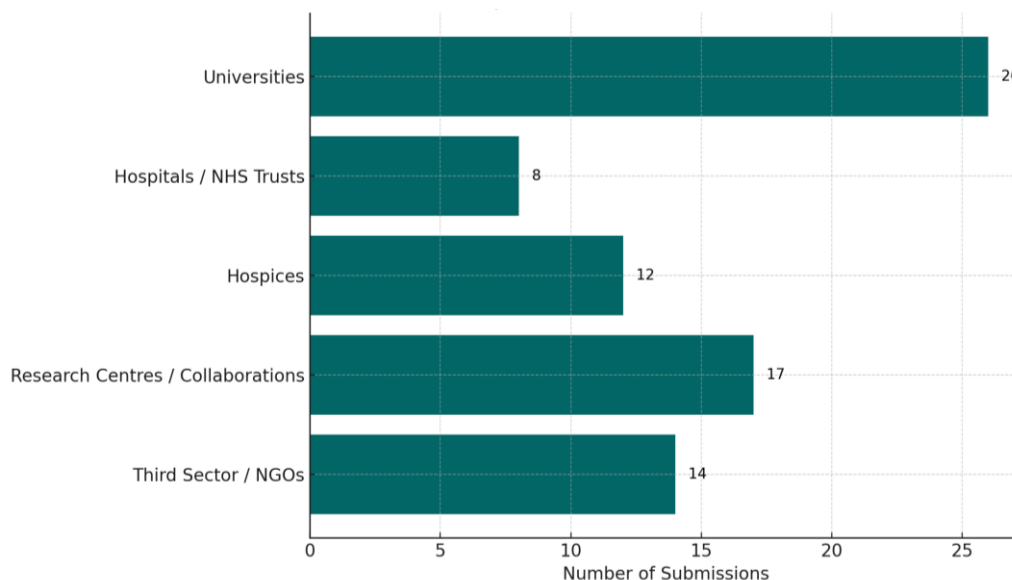


Figure 9 Institutional Representation in Academic Submissions (n=77)

Universities (Academics, Professors, Clinical Researchers):

9× Physicians

10× Nurses

7× Other (Social Scientists, Health Economists, Psychologists)

Hospitals / NHS Trusts (Consultants, Hospital-based Nurses, Integrated Care Leaders)

5× Physicians

2× Nurses

1× Other

Hospices (Hospice Nurses, Research-active Clinicians, Educators)

2× Physicians

5× Nurses

5× Other

Research Centres / Collaborations (PEoLC networks, university-linked collaborations)

4× Physicians

6× Nurses

7× Other (Research Fellows, Interdisciplinary Teams)

Third Sector / NGOs (Charities, Advocacy Organisations, International Bodies)

3× Physicians

2× Nurses

9× Other (Policy Leads, Bereavement Workers, Global Health Experts)

What could be improved?

When asked how they would improve coordination of services, academics highlighted the need for better digital systems and data-sharing infrastructure. Many respondents stressed that a lack of interoperability between services impedes integrated care and leads to duplication and delays. Education and training were also central: numerous submissions called for universal palliative care training across all sectors, particularly for generalist health and social care staff.

Mandate specific data and digital systems at a national or ICB level... applications must access information across a variety of systems, accessible to staff, volunteers and patients”¹⁷

This aligns with the Commission’s call for improved digital interoperability to support joined-up care pathways and reduce avoidable hospital admissions. Chapter 10 of the Commission’s documented that many professionals receive little to no formal training in end-of-life care, contributing to inconsistent care quality.²

How to address service funding and commissioning?

When asked how to ensure better service funding and commissioning, responses called for ring-fenced and multi-year funding to avoid the fragmentation caused by short-term fixes. Submissions also emphasised the distinction between funding and commissioning, urging a more strategic approach that ties spending to outcome delivery. Several called for a national commissioning framework, underpinned by statutory minimum standards.

Embed multi-year funding cycles to allow for long-term planning and innovation”¹⁷

This directly supports the Commission’s recommendation that specialist palliative care should be commissioned by Integrated Care Boards (ICBs) and integrated with existing services to ensure adequate access for all populations. Furthermore, children’s hospice services require national commissioning or collaborative commissioning by a consortium of ICBs. This is consistent with Recommendation 2 in the Commission’s report on mandating and funding palliative care services in every area.²

How to address inequitable access to palliative and end-of-life care?

When asked how to address inequitable access to palliative and end-of-life care, many submissions raised deep concern about systemic inequities faced by underserved populations. Barriers cited included diagnostic bias (especially for non-cancer conditions), social

¹⁷ Academic written evidence submission

determinants (e.g., deprivation, rurality), and discriminatory attitudes toward minoritised groups. Academics strongly advocated for equity-based commissioning, culturally competent care, and better use of data to monitor disparities.

“The issue of equity is becoming increasingly recognised with the current interest in equity, diversity and inclusion. Ethnicity, gender, LGBTQ+ populations, homelessness, prisoners, learning disability and others all have access problems with palliative care, with a lack of understanding of what these communities have to offer. Phrases such as ‘hard to reach’ are a marker of the ways in which different communities are viewed from palliative care services.”¹⁷

“Proactively including minoritised groups in research and service design”.¹⁷

This is reinforced by *Volume 1*, which notes that patients from ethnic minority communities, rural areas, and those with dementia or learning disabilities face pronounced inequities in access and outcomes. The value of co-produced research and advocacy for greater inclusion of patients, carers, and the public in designing and evaluating services was emphasised. This directly aligns with the Commission’s recommendation for inclusive policy action and national monitoring of equity indicators.²

How to improve public understanding of palliative care?

On improving public understanding of palliative care, academics pointed to a widespread societal discomfort with discussing death and many felt deeper cultural change is needed. Respondents also called for normalising conversations about death in primary care and within families, and equipping both professionals and communities to support these dialogues.

We must increase public death literacy through schools, communities, and mainstream media”.¹⁷

This is consistent with the Commission’s call to improve public and professional understanding of what palliative care offers, and the benefits of early engagement with services, as well as the need for better communication skills training for frontline staff and early conversations about care preferences.²

What are the barriers to optimal care?

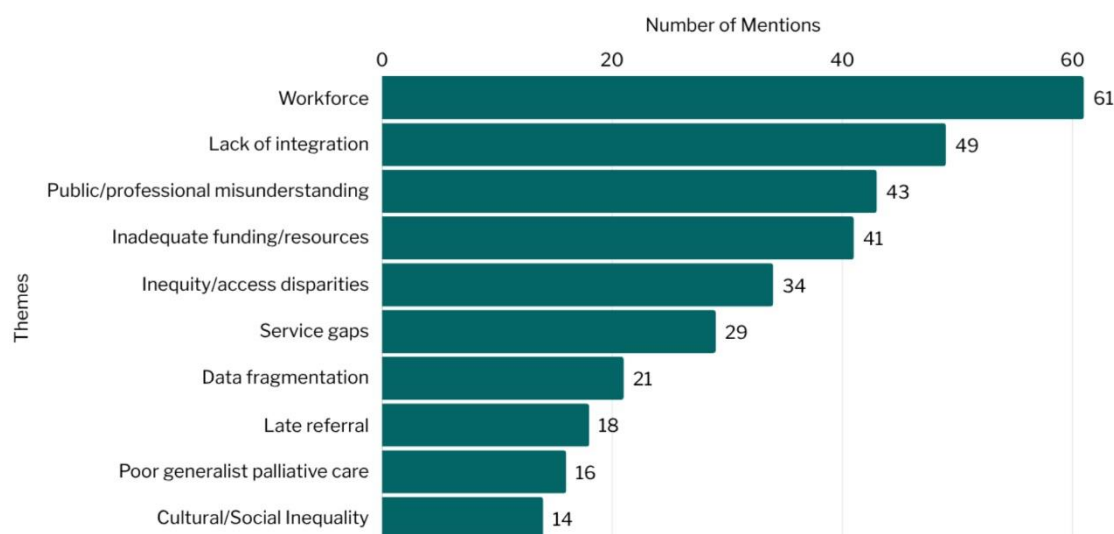


Figure 10 Academics' Top Barriers to Delivering Optimum Palliative Care and End-of-Life Care

When asked to identify the top three barriers to delivering optimal palliative and end-of-life care, academic respondents most frequently cited workforce-related issues, including staff shortages, insufficient training, and difficulties retaining skilled professionals. This was followed by concerns over poor service integration and fragmented coordination across sectors. Misunderstandings about what palliative care involves, both among professionals and the public, were also a widely recognised barrier, contributing to delayed referrals and underuse of services. Other recurrent challenges included underfunding, inequitable access, particularly for marginalised or non-cancer patients, and a lack of comprehensive out-of-hours provision.

Workforce Shortages and Training Gaps

A dominant theme across academic submissions was insufficient staffing and inadequate training for generalist palliative care.

“Insufficient staffing and inadequate time to provide generalist palliative care, including emotional support for patients and their families,”¹⁷

“An increasingly transitory, under-trained, poorly oriented generalist workforce,”¹⁷

These concerns are reflected in Volume 1 of the Commission’s Report, in Chapter 11, which discusses “critical shortages across nursing, social services, and palliative medicine,” and calls for investment in a competent, confident, and well-supported workforce.² Recommendation 4 was introduced by the Commission to address these workforce shortages and training gaps through improved education and training for all health and social care staff. Recommendation 5 ‘dual accreditation and recognition of prior experience’ allows for retired GPs to enter the palliative care workforce.

Lack of Integration Across Services

Academics frequently identified the lack of integration across health and social care services as a serious impediment to delivering optimal palliative care.

“Disjointed care”¹⁷

“Effective transfer of information”¹⁷

Volume 1, Chapter 6 of the Commission’s report confirms these challenges, noting that “the fragmentation of specialist palliative care services has resulted in inequity of provision, confusion over responsibility, and lack of support to the public and staff”.² Recommendation 8 calls to ‘Integrate health and social care data systems, including with outcomes data’ which will allow for seamless communication between providers, reducing duplication and unnecessary procedures, and improving integration between primary and secondary care.

Public and Professional Misunderstanding of Palliative Care

Stigma and misunderstanding around the role of palliative care were repeatedly identified as barriers. These perceptions delay access to supportive services. As stated in Volume 1, the Commission defines palliative care as, “improving the quality of life of patients and that of those important to them, such as their families, who are facing challenges associated with life-threatening illnesses, whether physical, psychological, social or spiritual. The quality of life of caregivers improves as well.”¹⁸ Palliative care offers support during bereavement. It should be noted that palliative care is potentially needed over prolonged periods, from diagnosis in some diseases in adults or in children with congenital life-limiting diseases. Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death.^{19, 2}

“Lack of knowledge and stigma associated around palliative care i.e. ‘doctors washing their hands of me’”¹⁷

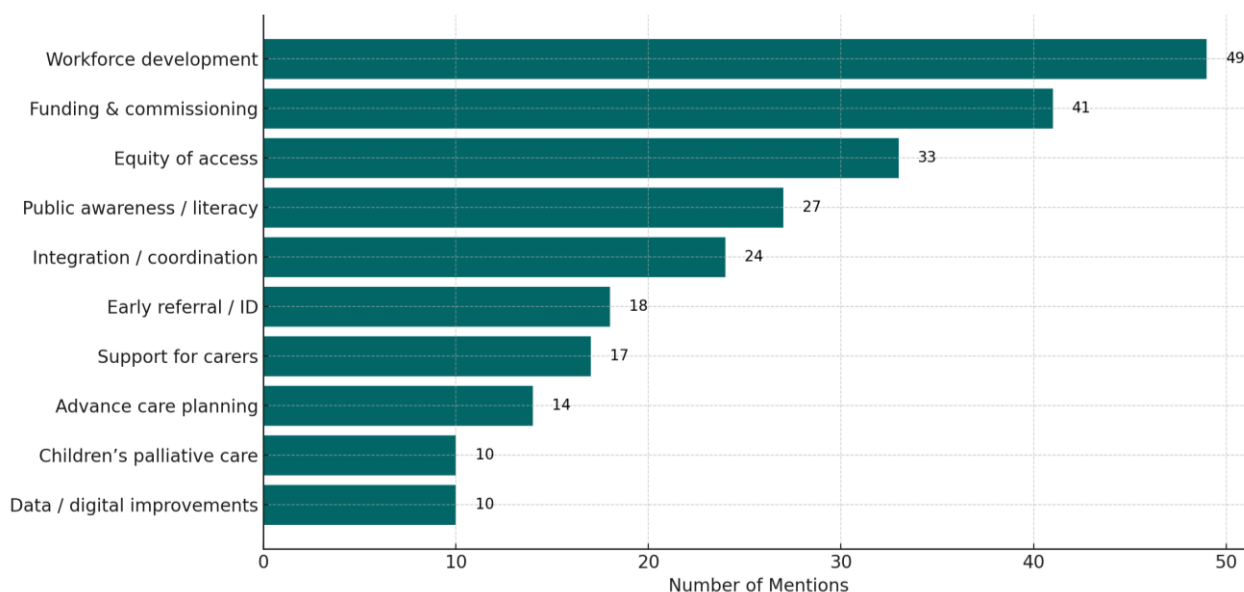
“Palliative care is frequently thought of as end-of-life care but it needs to be introduced earlier”¹⁷

Recommendation 10 seeks to ‘Improve understanding around palliative care, hospices and dying’ which will improve timely support during illness and bereavement and long-term social and employment outcomes.

¹⁸ World Health Organization. (2020). Palliative care. Retrieved from <https://www.who.int/europe/news-room/fact-sheets/item/palliative-care> Accessed on 8/4/2025

¹⁹ National Institute for Health and Care Excellence (NICE). (2021). Palliative care – general issues: Definition. Clinical Knowledge Summaries. Retrieved from <https://cks.nice.org.uk/topics/palliative-care-general-issues/background-information/definition> Accessed on 8/4/2025

What would most improve services?



In contrast, when asked what three changes would most improve services, respondents pointed to workforce development as the top priority, including mandatory training in palliative care across health and social care roles. Calls for reforming funding and commissioning were also prevalent, with many urging a shift toward equitable, needs-based models. Improving public awareness and death literacy was a recurring recommendation, alongside suggestions to strengthen integration, enable earlier identification of need, and provide better support for carers. The importance of accessible advance care planning, children's palliative care, and effective use of data and digital systems were also noted as key levers for improvement.

Workforce Development and Education

Academics strongly emphasised the need to prepare the entire health and social care workforce to meet growing palliative care demands.

“Prepare the entire workforce – appropriate to role and responsibility – for the predicted increase in demand for palliative care as the population ages”¹⁷

“Sustained investment... to enhance cross-disciplinary research-practice collaborations”¹⁷

Volume 1, Recommendation 4 of the Commission's report supports this theme, advocating for 'Education and training for all health and social care staff' as essential for system-wide improvement. Recommendation 5 of 'Dual accreditation and recognition of prior experience' also allows for greater workforce development and education.²

Figure 11 Clinicians' most cited improvements

Funding and Commissioning

Funding and commissioning reform was identified as essential to enable long-term improvements.

“Funding and commissioning need to be based overtly and explicitly on the best available research evidence”¹⁷

“We need a stronger evidence base... but research... is rarely conducive to the expectations of funders such as NIHR, meaning much needed research is not funded”.¹⁷

Respondents criticise investments in unproven interventions and calling for structural and financial support for care models that have demonstrated success. These align with Recommendation 6 of the Commission’s report Volume 1, which call for reform in funding mechanisms and the establishment of a robust research infrastructure to guide service development.²

Equity of Access

Many academics highlighted inequity in access to palliative care as a systemic failure.

“Any approach to tackling inequity should seek to address... shared needs, making care more inclusive for all... a collaborative, whole-system approach”¹⁷

“Regional variations... ensuring equitable access”¹⁷

This addresses the wider determinants of health such as low health literacy and social exclusion. These reflect the Commission’s findings in Volume 1, which highlights uneven provision and the necessity of a national framework to ensure fairness and standardised access to care.²

Children’s Palliative Care

Of the 77 submissions from academics, at least 18 of these submissions discussed children’s palliative care. Submissions highlighted inadequate access, poor integration and fragmentation of services, the emotional and financial burden on families, and the lack of training and confidence amongst professionals when delivering paediatric palliative care and end-of-life care. Academics reported that children often lack access to appropriate palliative care, particularly outside of cancer diagnoses or urban areas, and parents and carers face intense emotional, financial, and practical burdens when caring for a child with a life-limiting condition.

“Despite improvements in the past year, major gaps in 24/7 end-of-life care at home mean too many seriously ill children and their families are still unable to access the care they need

*because of where they live. Workforce shortages, funding shortfalls and a lack of accountability have resulted in high vacancy rates, underfunded services and inconsistent local leadership. Investing in the workforce, closing the £310 million funding gap and holding integrated care boards (ICBs) to greater account, would ensure families can access high quality children's palliative care, when and where they need it."*²⁰

Chapter Five: The Three Shifts

Patients

Hospital to Community

Submissions from patients, carers, and families reflect deep concern about the shift from hospital to community-based palliative and end-of-life care, revealing significant gaps between policy aspirations and lived experience. Many respondents described a sense of abandonment as local services diminished.

*"I live in Bridlington... We have no Hospice and York Trust has moved EOL care to North Yorkshire. The NHS has deserted our town... Make it [care] available nearer to home so I can visit"*⁵

*"She would have greatly benefited from regular community visits."*⁵

*"Travelling many miles daily to spend time with a very ill relative/partner is unacceptable."*⁹

*"The staff who work in hospices... should be able to provide 24 hour life line... to other professionals that are involved in caring for the person outside of 'normal hours'."*⁵

Respondents highlighted the strain caused by centralising care in distant acute hospitals. The lack of local hospices and accessible community services was frequently mentioned. There was a repeated perception that care at home was fragmented and impersonal, often delivered by professionals who appeared unwilling or unable to help. The emotional and logistical toll on families was also evident. Others emphasised the need for more consistent, round-the-clock support. Across these responses, there is a consistent message: while care closer to home is theoretically welcomed, in practice it can mean less care, more responsibility falling on families, and distressing gaps in support at a time when compassion, continuity, and competence are most needed.

Analogue to Digital

Many respondents pointed to poor communication and lack of coordination between services, suggesting that digital integration has yet to deliver promised improvements.

²⁰ Charity written evidence submission

“My mother received very little palliative care. She was linked to the GP, and the hospital communicated mostly through myself,”⁵

“Clinicians to liaise clearly and sympathetically with carers and family,”⁵

Respondents illustrated the continued dependence on informal communication rather than shared digital records, with some implicitly calling for better systems to support timely and consistent information-sharing. The failure to clearly record and relay patients’ wishes also emerged as a theme: with one respondent pointing to missed opportunities in care planning that more effective digital systems might have prevented. These experiences suggest that while the move to digital promises more personalised, coordinated, and efficient care, it currently falls short in practice. Respondents emphasised that without well-designed, interoperable systems and meaningful integration across services, the digital shift risks becoming another source of fragmentation rather than a solution to it.

Treatment to Prevention

Submissions strongly suggest that moving from treatment to prevention results in alleviating unnecessary suffering and missed opportunities for support. Respondents described systems that only respond in crisis, rather than anticipating decline and acting early.

“In the three weeks we knew that our son was dying, it was too late for us to explore with him his understanding of death, and for him to make choices,”⁵

“Palliative conversations are avoided until all treatments have been exhausted.”¹

Respondents illustrated how delays and rigid clinical protocols waste valuable time. The absence of timely recognition was a repeated theme. These accounts reveal a pressing need to reorient care models toward early identification, symptom management, and personalised support that prevents escalation—rather than reacting only when curative options have run out.

Clinicians

Hospital to Community

Many clinicians expressed warning that the current system is ill-equipped to manage the transition from hospital to community safely or effectively. While there is broad support for enabling patients to die in their preferred place, clinicians repeatedly flagged the lack of resources to make this possible.

“Vulnerability of community, hospice services suffering from a lack of money, the withdrawal of funding and no long-term financial stability to be able to develop services, especially out of hours”¹⁰

“The majority of people want to die at home and just 6% of people in the UK say they would prefer to die in a hospital.”²¹ ²⁰

“Local neighbourhood teams working with local communities”¹⁶

Workforce shortages, insufficient out-of-hours services, and fragmented commissioning models were frequently cited as barriers to safe care outside of hospital. Clinicians also emphasised that care in the community requires more than just transferring tasks- it demands continuous, relational support from skilled teams, with one submission calling for to ensure availability of care at home. Without robust community infrastructure, the shift away from hospital settings risks leaving patients and families without the support they need at the most critical time.

Analogue to digital

Clinicians emphasised that the shift from analogue to digital is essential for delivering coordinated, high-quality palliative and end-of-life care. Many described current systems as fragmented and inefficient, with poor communication between care settings.

“Working with the ICB to try to develop a dashboard of meaningful data”¹⁰

“Integration must be enabled through shared records, joint reviews, and clear commissioning levers that incentivise multidisciplinary collaboration and timely community responses”¹⁴

Others highlighted the value of shared care records, stressing that patient wishes and clinical information must be accurately recorded and updated and made accessible to all involved, including ambulance services, hospices, and social care. The lack of interoperability between IT systems was seen as a major barrier, preventing seamless transitions and timely interventions. Clinicians also called for innovation, including research into how AI could help identify those nearing the end of life, enabling earlier support and referral. Robust digital infrastructure is critical to achieve integrated, person-centred care.

Treatment to Prevention

Clinicians advocated for a shift from reactive treatment to preventive, proactive care in palliative care and end-of-life settings, emphasising early identification and meaningful engagement.

“[The Dorset Intelligence and Insight Service] enables proactive identification of people who may be in their last years of life, so that appropriate conversations, care and support can be enacted.”¹⁰

²¹ Marie Curie (2024). Public attitudes to death, dying and bereavement in the UK re-visited: 2023 survey. https://www.mariecurie.org.uk/globalassets/media/documents/policy/policypublications/2024/n401_padd_report_final.pdf

“Patients introduced to hospice care too late in their disease trajectory.”¹¹

This allows teams to intervene earlier, reducing unnecessary hospital admissions and improving quality of life. By learning from bereaved families and embedding their feedback into training and governance, clinicians aim to move away from last-minute interventions toward care that is planned, person-centred, and aligned with patient values.

Academics

Hospital to Community

Academic submissions offered strong support for shifting palliative and end-of-life care from hospitals to the community but also highlighted the risks and requirements of doing so effectively. Submissions pointed to significant gaps in infrastructure and workforce, and concern about inequity.

“There is very little investment in preventative community care to reduce hospital admissions and rapid discharge home when fit for discharge”²²

“Home palliative care is already delivered, but is currently provided very inconsistently (and sometimes not at all).”²³

“Different parts of the country will have different constellations of inequity and inequitable access to PEOLC”¹⁷

Together, these insights stress that while the shift to community care is supported in principle, it must be underpinned by investment, planning, and evaluation to avoid displacing burden onto families and under-resourced services.

Analogue to digital

Academic submissions supported the transition from analogue to digital in palliative and end-of-life care, emphasising its critical role in improving coordination, communication, and continuity.

²² Third Sector Organisation written evidence submission

²³ Clarke, G., May, P., Cook, A., Mitchell, S., Walshe, C., Bajwah, S., Yorganci, E., Kumar, R., Fraser, L.K., Sleeman, K.E., Murtagh F.E.M. (2025). Costs and cost-effectiveness of adult palliative and end-of-life care. Evidence briefing summary. London: National Institute for Health and Care Research (NIHR) Policy Research Unit (PRU) for Palliative and End-of-Life Care. Available at: <https://www.kcl.ac.uk/nmpc/assets/research/costs-and-cost-effectiveness-of-adult-palliative-and-end-of-life-care-evidence-briefing-summary.pdf> Accessed on 1 April 2025

“Digital coordination: In 2010, an NHSMail pilot in south London showed how secure information sharing between social care teams and healthcare professionals improved coordination for end-of-life care”²²

“NHS England and local IT system suppliers need to collaborate to harmonise local IT systems so all health professionals have access to shared electronic patient records across GP, community and hospice interfaces, including remotely in patients’ homes. Continuing with current levels of lack of shared access risks delayed and unsafe prescribing.”¹⁷

Respondents stressed that digital coordination is essential for shared understanding among professionals and for respecting patient preferences. These comments reflect a strong consensus that without interoperable systems and clear data-sharing protocols, care remains fragmented and reactive. Academics called for standardisation and investment in digital infrastructure to support real-time access to care plans, symptom management records, and advance decisions. This shift is viewed as foundational to delivering timely, person-centred care and reducing the burden on patients and families navigating disconnected services.

Treatment to prevention

Academic submissions strongly supported a shift from treatment to prevention in palliative and end-of-life care, urging earlier identification and proactive support to improve outcomes and reduce avoidable interventions.

“Early access to palliative care for people with liver disease can lead to acute service use reductions and reduced bed days”²⁰

These perspectives advocate integrating palliative care earlier in the disease trajectory, shifting away from a crisis-driven model and focusing instead on symptom control, planning, and psychosocial support well before the final days. This preventive orientation, academics argue, is essential for reducing suffering, hospitalisation, and the strain on both families and the wider health system.

Overall Findings:

From all 532 written evidence submissions, there were clear themes of barriers and priorities to improving palliative care and end-of-life care.

The Need for Adequate and Sustainable Funding

There was strong and widespread concern across all submissions regarding inadequate, inconsistent, and unsustainable funding for palliative care services, particularly for hospices and community-based care. Respondents emphasised the urgent need for a centralised, needs-based funding model that ensures long-term, stable financial support across all settings. Current funding models—often a mix of charitable, public, and private sources fail to align with population needs and contribute to inequities and uncertainty in service provision.

“Ensuring long-term financial security would enable hospices to expand services, retain skilled staff, and meet growing demand.”¹⁶

“Proper consistent funding will end the postcode lottery and inequity”¹⁰

One respondent proposed that reinforcing the sentiment that reliance on fragmented or short-term sources hinders the development of equitable and integrated care. To address this, one key recommendation was to mandate and fund specialist palliative care in every area, commissioned by Integrated Care Boards (ICBs), integrated with general services, and made available on a 7-day basis with 24/7 advice access. Children’s hospices were identified as requiring national or collaborative commissioning to ensure equitable access. Services should operate through multidisciplinary teams, coordinate with social care, and be accessible at the time of life-limiting diagnoses or advancing frailty. In addition to ethical and equity imperatives, improved funding for specialist palliative care offers economic benefits by reducing costly hospital admissions, unnecessary acute interventions, and emergency department visits, while enhancing well-being through compassionate, personalised support that improves quality of life.

Access and Equity

Many respondents highlighted persistent inequities in access to palliative care, with barriers and disparities particularly affecting those in rural areas, underrepresented groups, those with non-cancer conditions, and socioeconomically disadvantaged communities.

“Equality of access for complex needs patients and their carers. Professionals being able to access services locally, especially where transport is an issue in coastal and rural areas.”⁹

“The issue of equity is becoming increasingly recognised with the current interest in equity, diversity and inclusion. Ethnicity, gender, LGBTQ+ populations, homelessness, prisoners,

learning disability and others all have access problems with palliative care, with a lack of understanding of what these communities have to offer.”²²

Respondents emphasised the need for local services, particularly in areas with limited transport options such as coastal and rural regions. To expand access, respondents advocated for more hospice beds, greater home care provision, and earlier identification and support for individuals approaching the end of life. Specific concerns included poorer access for older people, those with learning disabilities, and minority ethnic communities.

In response, a key recommendation was to improve rapid access to community-based services by commissioning fully integrated 24/7 support systems, led by the Integrated Care Boards (ICBs), by 31 March 2028. This includes having a responsive human voice to answer calls, immediate access to clinical records, and coordinated support from community clinicians, pharmacy services, social care, rapid response teams, and access to equipment and medications. Such services are essential not only for improving equitable access but also for preventing unnecessary hospital admissions, reducing healthcare costs, and enabling patients to remain in familiar environments—thereby reducing anxiety and enhancing emotional well-being for both patients and their families.

Workforce and Training

Staff shortages and workforce burnout were identified as major challenges across all submissions, particularly within community settings where the shortage of trained professionals has led to delays in care. Respondents called for the training of more palliative care professionals, the creation of clearer career pathways, and greater support for staff wellbeing.

“The majority of staff working in care and nursing homes, and many front-line NHS staff, do not receive any training in death, dying, and grief, despite encountering this frequently”²⁴

“Shortages lead to doctors working as ‘good will’ to cover rota gaps, leading to burnout, and unsafe care provision.”¹⁰

Lack of training results in both lower quality care and negative impacts on staff morale and retention. Burnout and lack of specialist training were widely cited. To address this, a key recommendation was the implementation of mandatory palliative care training for all health and social care staff, beginning in undergraduate education from September 2026. This training should include early identification of patients who would benefit from palliative care, enhanced communication skills, and ongoing, specialist-level training for those in palliative roles. Time for continuous professional development must also be protected.

Another recommendation focused on dual accreditation and the recognition of prior experience, particularly for general practitioners with specialist palliative training, to support career mobility and retain senior doctors skilled in community care. These measures aim to

²⁴ End-of-life doula written evidence submission

reduce complaints, ensure timely referrals, and improve the rapid escalation of care for complex needs, while also strengthening the workforce through better education, retention, and recognition of expertise.

Care Coordination and Integration

There was widespread frustration with the fragmentation and poor coordination of palliative care services, particularly between hospitals, hospices, primary care, and social services. Respondents repeatedly identified disjointed and duplicated care, as well as patients being “lost in the system” due to inadequate integration between sectors—such as health and social care—and across regions. A lack of coordination between hospital and community teams was described as a major systemic weakness. To address this, respondents called for better care integration through local shared dashboards, the incorporation of advance care plans, and especially the development of secure, integrated digital systems that allow real-time data sharing among all relevant providers.

“Successful collaborative care requires a real-time sharing of data across all providers. We recognise that digital integration underpins both collaborative system working and communication across all services.”²⁵

“Disjointed systems with different electronic care records and poor co-ordination of care, leading to confusion for patients and families and reduces access to the right service for their needs”¹⁴

A key recommendation was to create fully integrated health and social care data systems that ensure key patient information is accessible to general practitioners, ambulance services, emergency departments, care homes, social care providers, specialist palliative care teams, and hospital staff, across all settings, including environments like prisons.

Improved data sharing not only enhances care quality and continuity but also reduces unnecessary tests and procedures, delivering cost savings and enabling more effective resource allocation. Importantly, it helps prevent inappropriate hospital admissions and fosters patient confidence by ensuring care is consistent with their preferences and needs, thereby improving overall satisfaction and reducing stress for both patients and families.

Timely referrals, identification, and conversations

Submissions consistently emphasised the importance of early, honest, and compassionate communication about prognosis and care preferences, alongside greater public understanding of palliative care. Many respondents noted that referrals to palliative care often occurred too late, sometimes only in the final days of life, after aggressive treatments had been exhausted—limiting the opportunity for meaningful support and informed decision-making.

²⁵ Commissioner written evidence submission

“Sensitive and honest discussion about prognosis and how quickly things were changing.”⁵

To address this, it was recommended that following a diagnosis or the progression of a life-limiting illness, every patient should have the opportunity to discuss and document their personalised wishes and care plans, with these reviewed regularly in collaboration with their family and clinicians.

Training for clinicians in compassionate, open, and honest communication is essential to ensure patients feel heard, supported, and able to maintain control and independence despite the progression of their illness.

Such communication reduces complaints, unnecessary interventions, and the emotional burden on families, while enhancing patient empowerment and quality of life. In parallel, broader public education is needed to normalise discussions about palliative care, hospices, and dying. This should begin with age-appropriate education in schools and extend into community outreach, including bereavement services and widely accessible materials to support engagement with the realities of death and dying. Increasing public understanding in this way promotes earlier engagement with palliative care services, improves communication, reduces stigma, and supports better outcomes for patients and bereaved families, including reduced morbidity and improved long-term social and employment prospects.

Appendix

Commission's Key Recommendations in Summary:²

1. Develop a National Strategy for palliative care and end-of-life care

A National Strategy must be developed setting out a framework for the commissioning and delivery of specialist palliative care and end-of-life care services, and the workforce requirements to implement this, recognising the general palliative care responsibilities of all working in health and social care.

The strategy should set short- and longer-term milestones. Annual reporting on key milestones in the Strategy must be a Ministerial responsibility of the Department of Health and Social Care.

2. Mandate and fund 24/7 specialist palliative care, working with coordinated general care in every area

Specialist palliative care must be commissioned at a defined level based on local need, recognising the contribution of their local hospice. For any patient with palliative care needs whose distress is not beginning to ameliorate within a maximum of 48 hours, advice should be sought from the local specialist service.

Benefits: Amends inequity; reduces expensive unplanned hospital care; prevents crises and unnecessary Emergency Department attendances; improves symptom control and support including at the end-of-life; enables coordinated care; provides better long-term outcomes for the bereaved of all ages; provides a resource of skills and knowledge to other health and social care services in the area for advice and for training.

3. Improve rapid response to advice and access to community services

Expand rapid response out-of-hours support, including access to medicines and equipment, in all settings. A single telephone point of access is required for 24/7 advice to professionals in all settings, and to families and carers caring for a patient at home, and with capacity for specialist palliative care rapid response visiting 8 am-8 pm, with advice available at other times to generalist teams.

Benefits: Lowers costs from and reliance on emergency services and unplanned hospital care; helps patients stay at home during potential crises; provides support to families, carers and other professionals.

4. Education and training for all health and social care staff

Build confidence across the wider workforce, ensuring more staff are equipped to communicate with skill and kind honesty, and to recognise palliative care needs and assess problems. Palliative care must be a core part of undergraduate programmes for medicine, nursing and allied health professionals with training modules available for all those in practice in health and social care. Clinicians must be able to work collaboratively, able to seek the interventions patients need for good management.

Benefits: More efficient care; better patient experiences and evaluations, with fewer complaints; facilitates timely referrals and care; improves communication and patient outcomes; wider benefits for all people with long-term conditions.

5. Dual accreditation and recognition of prior experience

We strongly recommend dual accreditation in specialist palliative medicine is available for those training in general practice, and to allow accreditation of experience in general practice.

Benefits: Support the shift from hospital to community; retain in the workforce general practitioners who wish to move on from GP practice.

6. Fund research to improve care, especially evaluating community-based interventions and treatments

Generate evidence for an Impact Centre, which will collate and disseminate evidence on where resources are most cost-effective, and including research undertaken in clinical settings provided by all health and care professionals.

Benefits: Identifies cost-effective treatments and models of care delivery; supports innovation in community care; advances care quality and equity; takes advantage of digital innovations; wider benefits for people with long-term conditions and care needs.

7. Support informal carers and families

Recognise and resource carers, providing tailored support around dying, including bereavement issues.

Benefits: Strengthens unpaid care; reduces risk of carer burnout and hospital use; protects carers mental health and fosters resilience, and supports carers to manage their own grieving processes.

8. Integrate health and social care data systems, including with outcomes data

Integrate secure data systems for seamless communication between health and social care providers. Move to recording symptoms, concerns and outcomes, not only processes.

Benefits: Reduces duplication and unnecessary procedures; improves care delivery; wider benefits for all people with long-term conditions; improves integration across primary and secondary care and across clinical specialties in a unified electronic shared record-keeping system.

9. Ensure compassionate, open, and timely communication, supporting future care plans

Give every patient the opportunity to communicate their own, personalised wishes to plan for future care, at the time of being diagnosed with a terminal illness, progression of a life-limiting illness or during uncertainty. This will be a dynamic document, regularly reviewed with the patient and those close to them, such as their family. Clinicians will be trained in

kind and honest communication and developing future plans, including for care, with patients and their families.

Benefits: Improves kind and honest communications, and listens to patients and families concerns, which has been a key failing noted in other reviews.

10. Improve understanding around palliative care, hospices and dying

Promote public and professional understanding of what palliative care can offer, and how to access timely support, particularly care around dying, to avoid distress. Death is a normal part of life.

Benefits: Timely support during illness and bereavement; improved long-term social and employment outcomes for the bereaved of all ages.