Association for
Palliative Medicine

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Association for Palliative Medicine of Great Britain and Ireland (APM) response to the Palliative Care Royal Commission

The Association for Palliative Medicine of Great Britain and Ireland (APM) welcomes the opportunity to respond to the Commission on End-of-Life Care. We commend the Commission's focus on improving palliative and end-of-life care (EoLC) across the UK. As the leading professional body for palliative care, we offer the following insights and recommendations to inform the Commission's work.

This document is in the sequence of the questions outlined in the 'call for written evidence' but with elaboration on each point.

In what capacity are you providing evidence?
Our membership is one of the largest palliative care organisations in the world with over 1,400 and is made up of predominantly (90%) of **physicians**, but we also have membership including, **nurses, allied health professionals, commissioners, academics and researchers**. Thus, we are representing a broad group, all united in focusing on specialist palliative care (SPC). The APM also represents all the devolved nations and Ireland alongside England. The focus in this document is predominantly England and Wales.

In what setting do you work?
The APM itself does not provide any direct care however our membership works across many settings, including: **Community, Hospice, Hospital, GP/Primary Care, Charity, Local authority social services, Criminal justice (i.e. prisons)**. Our membership also includes **academics and researchers working throughout the UK and internationally**. Our membership thus works for the NHS, Health and Social Care, Universities and Charitable sector alone or in combination.

Introduction

Describe what you are proudest of in your provision of Palliative and End of Life Care
The APM is proud to be the professional body for those working in, or interested in, Palliative Care. The APM provides clinical leadership, care and support to its membership with the overarching aim to prevent and relieve suffering for people with life-limiting and life-threatening illness. It originated out of the RCP, but stands separate.

To help the rest of the questions, we would like to outline some current key features to be able to build onto our answers.

Defining nomenclature

End-of-life care, as defined by the World Health Organization (WHO), refers to care provided in the **last year of life**. This care encompasses physical, psychological, social, and spiritual support for patients and their families.

Palliative care is **both a concept**, applicable at any stage of a life-limiting illness, and also can be a **specialist medical profession**.

Generalist palliative care is provided by **all** health care professionals, who manage symptoms and co-ordinate care. There are various standards of practice of generalist palliative care, with some healthcare professionals more equipped than others.

Specialist palliative care (SPC) is a **recognised medical specialisation** delivered by multidisciplinary teams with advanced training, addressing complex needs such as refractory pain, psychological distress, or intricate family dynamics. This dichotomy mirrors the relationship between GPs and hospital specialists, where generalists manage routine cases and refer to specialists when complexity arises. The reason for outlining this, is both are vital to a healthy integrated system.

The Population Demographics

The Office for National Statistics (ONS)[1] projects a significant increase in the number of people requiring palliative care due to an ageing population and the rising prevalence of chronic illnesses. **By 2040, it is estimated that the number of deaths annually in England and Wales will increase by 25%**, with a corresponding rise in the need for palliative care services (Nuffield Trust, 2017). This translates as **60% increase in over 65's and a 40% increase in those over 80 years old** (ONS). This is not a prediction as 'may or may not' happen, these people are alive today and are getting older. This underscores the urgency of integrating palliative care into the NHS Long Term Plan and ensuring sustainable funding and workforce planning.

Complexity of Patients and Changing Demographics

Specialist palliative care (SPC) teams are increasingly managing two distinct but equally complex patient groups: **older, frail patients with multiple comorbidities** and intricate social, spiritual, and physical needs, and **younger patients with complex, conditions**. Both groups are a success of modern medical treatments and present with multifaceted needs, including challenging symptom management, psychological distress, and significant social care requirements.

The Marie Curie report (2023)[2] highlights that 25% of people accessing SPC are under 65, reflecting a notable shift in the demographic profile of those requiring such services. This growing complexity, coupled with the diverse needs of these patient groups, underscores the urgent need for a robust, integrated approach to care delivery that is both flexible and responsive to individual circumstances.

The demographics of patients requiring specialist palliative care are increasingly polarised between the **multi-comorbid elderly and the complex young**. Collaboration between geriatricians and palliative care specialists ensures that older patients with multiple comorbidities receive holistic, person-centred care that meets their specific needs. This partnership enhances quality of life and ensures dignity for patients, while also supporting their families during challenging times. Timely access to specialist palliative care expertise is essential for all those who need it, to manage the unique challenges of end-of-life care, including complex symptom management and psychological support.

Cost of Last year of life

A recent study by the Nuffield Trust and the Health Economics Unit, commissioned by Marie Curie, examined public expenditure on individuals in their last year of life in the UK. The study estimated that **in 2022, public spending amounted to approximately £22 billion, equating to £33,960 per person who died**.[3] This expenditure was distributed across health care (over £12 billion or 56%), social care (almost £5 billion or 22%), and social security (around £5.5 billion or 25%).

Within health care spending, hospital care dominated, accounting for 81% of the expenditure, with 56% directed towards emergency hospital care. Specifically, hospital in-patient care represented 73% of health care costs (£8.6 billion). In contrast, primary and community health care received only 11% (£1.3 billion), and public funding for independent hospices constituted less than 4% of health expenditure. Including voluntary contributions, hospice care still accounted for just 8% of health spending. **Consequently, for every £5 spent on health care in the last year of life, £4 was allocated to hospital services, with £2.80 of that on emergency care.**

Social care expenditure primarily covered residential and nursing home care, comprising 63% (£3 billion) of the total social care spending. Regarding social security, the State Pension was the largest component, making up almost 90% (£4.9 billion) of the expenditure for individuals in their final year.

These findings highlight a significant cost reliance on hospital-based care during the last year of life. However there is an absence of data to describe what hospital care is being provided to people to cause this cost – **what is adding benefit, what is a burden and what it might be possible to provide outside hospital** remains unclear. Future service mapping is also constrained by a lack of joined up clinical information systems to chart individual service use across the system.

What is the state of Palliative Care?

Palliative and end-of-life care in the UK faces significant challenges, leading to many individuals not receiving the support they need during their final stages of life. The APM would outline the recent Marie Curie 'Time to care' report (Sept 2024).[4,5]
The Key issues outlined in this include:

Symptom Management and Support Deficiencies:

A substantial number of patients experience severe symptoms in their final week, with **over one-third affected by pain (34%) and breathlessness (40%)**. Additionally, **nearly two-thirds (64%) of unpaid carers report constant anxiety regarding the patient's illness** or treatment, and more than a third (38%) observe that the patient felt depressed most or all of the time during their final week. **Accessing palliative care medicines, especially outside regular hours, remains a significant barrier**.

Inadequate Support for Unpaid Carers:

Unpaid carers often lack the necessary support and information, with many feeling unprepared for their caregiving roles. This lack of support can lead to increased stress and negatively impact the quality of care provided to patients.

Hospital:

Given the above data regarding the costs of end-of-life care, hospitalisation is disproportionately large and although sometimes necessary, data would suggest this could be reduced.[6]

Workforce and Funding Challenges:

The palliative care sector as a whole is experiencing **workforce shortages and financial constraints**, hindering the delivery of comprehensive care. Both the NHS and charitable hospices face extreme financial pressures, and long-term investment in both the generalist palliative care workforce in primary and community care and specialist palliative care has been insufficient to meet the rising demand.

The recent national insurance rise has disproportionally effected care homes, GP's and hospices - the predominant providers of palliative care.

Recent Developments in Funding for Hospices

Recently (Dec 2024), a one-off payment of £100 million was announced to support hospice services, with the aim of funding improvements such as refurbishments, IT system upgrades, and enhanced facilities for patients and visitors. While this injection of funds is a welcome step, it is important to note that this is not an ongoing commitment. In fact, the £100 million only covers a single year of the hospice sector's collective deficit, which stands at £77 million, as highlighted by Hospice UK.

This shortfall underscores the precarious financial situation facing hospices, driven primarily by rising costs and increasing demand for services. Without sustained funding, the sector will continue to struggle to meet the needs of patients and their families.

For further details, please refer to the following sources:
Hospice UK: Hospice Sector Facing Collective Deficit of £77m
UK Government: Biggest Investment into Hospices in a Generation

While the recent funding is a positive step, long-term solutions are urgently needed to ensure the sustainability and resilience of hospice services across the UK.[7,8]

There is a difference between 'funding' and 'commissioning'. Funding is financial support given to an organization or project with flexibility on how it's used within broad guidelines. Commissioning is the process of purchasing specific services or projects with clear deliverables and oversight. The APM would recommend commissioning of SPC services matched with inflation rather than one-off payments with no outcome or accountability outlined.

Health and Care Act 2022

Baroness Ilora Finlay's amendment to the Health and Care Act 2022,[9] which **places a legal duty on Integrated Care Boards (ICBs) to provide palliative care services**, has been a landmark step towards achieving equitable access to care. However, close monitoring of implementation is essential to ensure that ICBs prioritise palliative care within their budgets and service planning.

A 2023 survey of ICBs, with a 62% response rate, revealed significant gaps in understanding and provision.[10] Only 35% of ICBs reported that they significantly or fully understand the palliative and end-of-life care (PEoLC) needs of their local population. This lack of understanding makes it difficult to assess whether ICBs are effectively rolling out PEoLC services or if current provisions are adequately meeting local needs. **Furthermore, just three ICBs indicated that they commission core components of the Ambitions Framework**[11] to a significant degree, highlighting a concerning shortfall in alignment with national standards.

The survey also found that only 54% of ICBs believe current investment in PEoLC services is sufficient to meet needs to at least a moderate extent.[10] This suggests widespread underfunding, leaving ICBs unable to commission services that match demand. Additionally, access to critical services remains limited: **only 20% of ICBs reported commissioning 24/7 access to care advice and support for PEoLC, and just 25% provided 24/7 access to PEoLC medicines**. A separate review further underscored the lack of prioritisation, revealing that less than 25% of Integrated Care System (ICS) strategies identified PEoLC as a priority, area of focus, or ambition. [12]

These findings highlight a pressing need for stronger commitment, better resource allocation, and clearer strategic focus to ensure that palliative and end-of-life care services are adequately commisioned, understood, and prioritised across the UK. Without these changes, the vision of equitable access to high-quality PEoLC will remain out of reach for many.

Purpose of this document

While the primary focus of the APM is on specialist palliative care (SPC), we deeply understand and champion the vital inter-relationship between specialist and generalist palliative care providers. **Specialist palliative relies on a strong foundation of skilled generalist care** to identify patients with palliative care needs, provide initial support, and refer complex cases to specialists. Conversely, generalists benefit from the expertise, guidance, and resources that specialists provide, particularly for patients with complex symptoms or psychosocial needs. This mutual interdependence ensures that patients receive seamless, high-quality care tailored to their individual needs.

The APM is committed to fostering this collaborative relationship, recognising that both generalist and specialist palliative care must be well-supported, resourced, and integrated to deliver the best outcomes for patients and their families.

Barriers

What are the top three barriers to delivering optimal Palliative and End of Life Care

Below are the top three barriers to providing optimal palliative and end-of-life care, each summarised in under 100 words. These challenges exist within the broader context outlined above. While the severity and nature of barriers may vary across healthcare settings, the APM highlights these three as they transcend all settings:

1) Lack of Priority
2) Insufficient Resources
3) Misunderstanding of Palliative Care

1. Lack of Priority

Specialist palliative care is rarely perceived as a high-priority service, and a critical component of healthcare. In an organisation, such as the NHS, where there is reliance on historical budgets, being a relatively new field (50 years) is a challenge. Hence, SPC is deprioritised in favour of other medical services with more tangible or measurable outcomes. As a result, palliative care has been chronically underfunded, with a significant portion of its funding relying on charitable contributions rather than systemic investment.

2. Insufficient Resources

Despite the legal obligation to provide palliative care in England, the reality falls short of meeting the current and growing demand. An ageing population, chronic underresourcing and increasing prevalence of chronic illnesses have escalated the need for palliative care services. However, resources – including funding, staffing, and infrastructure - remain inadequate across all healthcare settings. This resource gap creates significant challenges in delivering timely, comprehensive, and equitable care to patients and their families.

3. Misunderstanding of Palliative Care

Palliative care is an holistic approach to improving quality of life for patients with life-limiting illnesses. However, the core principles of palliative care are often misunderstood by the general public and even some healthcare professionals. Palliative care may be mistakenly associated with "giving up"; being solely for the final days of life, or with “killing the patient”. These misconceptions can lead to reluctance in seeking or accepting palliative care services. Addressing this barrier requires widespread public education to clarify the purpose and benefits of palliative care, as well as building confidence that patients will receive compassionate, supportive care tailored to their needs.

Recommendations

What are the top three things you would change to improve the service

The answer to this question depends on the specific settings in which our members operate. However, to provide an overarching perspective, the APM would propose the following three key changes to significantly enhance palliative and end-of-life care services across all settings:

1) Integration of Specialist Palliative Care into the NHS Long-Term Plan
2) Clear specification of palliative care services including specialist palliative care (SPC) for accurate commissioning purposes, whilst aiming for 100% funding of SPC
3) Expansion of SPC workforce and funding to match population and location needs

1. Integration of Specialist Palliative Care into the NHS Long-Term Plan

Specialist palliative care (SPC) must be formally integrated into the Health Service and integration into the NHS Long-Term Plan is a good initial step to ensure it is recognised as a core component of healthcare delivery. Currently, specialist palliative care is often treated as an add-on or optional service, leading to inconsistent access and prioritisation. By embedding it within the NHS's strategic framework, specialist palliative care should receive the attention, funding, and policy support it requires and deserves. This integration would also facilitate better coordination between all palliative care services and other healthcare provisions, ensuring a seamless patient experience across primary, secondary, and community care settings.

2. Clear specification of palliative care services including specialist palliative care (SPC) for accurate commissioning purposes, whilst aiming for 100% funding of SPC

There is a pressing need for **clear, standardised specifications outlining what palliative care services in all settings should provide, entail and how they should be delivered**. For the ICBs to commission 'appropriate' services for their population it needs to both have a clear specification on what it is commissioning and responsibility with accountability to provide those services.

The ultimate goal should be in achieving 100% statutory funding of specified SPC services appropriate for the location and population in-keeping with all other specialist services. Currently, a significant portion of SPC funding relies on charitable contributions, which creates instability and inequities in service provision. **A National strategy outlining many elements within this document for both specialist and generalist palliative care may be a solution** as it should ensure services become more sustainable, consistent, and accessible to all who need them, regardless of location or socioeconomic status.

It is worth noting that Republic of Ireland has achieved this aim of 100% funding for SPC.

3. Expansion of Specialist Palliative Care workforce and funding to match population and location needs

The demand for palliative care is growing rapidly due to an ageing population and the increasing prevalence of complex, chronic conditions. However, the current workforce and funding levels are insufficient to meet this demand. To address this, there must be a concerted effort to **grow the specialist palliative care workforce through targeted recruitment, training, and retention strategies.** Additionally, funding must be increased to match the scale of population needs, ensuring that services are adequately resourced to provide high-quality, person-centred care. This expansion would not only improve patient outcomes but also alleviate pressure on other parts of the healthcare system by reducing unnecessary hospital admissions and enabling more patients to receive care in their preferred setting.

Recommendation 1: Integration of Specialist Palliative Care into the NHS (starting with integration into the NHS Long-Term Plan)

Recommendation 2: Clear specification and monitoring of palliative care services including specialist palliative care (SPC) for accurate commissioning purposes, whilst aiming for 100% funding of SPC

Recommendation 3: Expansion of Specialist Palliative Care workforce and funding to match population and location needs

Specific Recommendations

Beyond the overarching "top three" recommendations outlined earlier, there are numerous more specific measures that would be crucial for their effective implementation. As previously mentioned, the **development of a national strategy for palliative care would be the ideal framework to guide these efforts**. Such a strategy would provide a cohesive, co-ordinated approach to addressing the challenges in palliative and end-of-life care. Below are some key components that could form part of this national strategy:

Recommendation 4: The APM urges the Commission to hold commissioners (ICBs) responsible and accountable for delivering on this obligation for both generalist services and specialist and to provide clear guidance on minimum and appropriate service standards, specifications and metrics.

National Strategy

Effective commissioning of palliative and end-of-life care (PEoLC) is currently hindered by **the absence of a national strategy, inadequate or incomplete guidance, and a poor understanding of local needs due to the lack of agreed, patient-centred, and meaningful data collection.** These gaps create significant barriers to delivering consistent, high-quality care that meets the diverse needs of patients and their families.

To address these challenges, statutory guidance for 'Integrated Care Strategies' and 'Forward Plans' must explicitly include the legal requirement to commission PEoLC services. This guidance should also emphasise the need to involve both specialist and generalist providers of PEoLC, cover all life-limiting conditions, and ensure services are available across all settings. Crucially, the development of a detailed national strategy for PEoLC is essential to **provide clear direction and support for commissioning bodies,** enabling them to deliver equitable, high-standard care.

A major obstacle to effective commissioning is the insufficient understanding of local population needs. Without a nationally agreed framework for assessing PEoLC needs, commissioning decisions are often made in the dark. **The absence of a standardised national data collection system further compounds this issue,** as it prevents the demonstration of effective service delivery and the identification of gaps in provision.

While just over half of Integrated Care Boards (ICBs) report commissioning joined-up and co-ordinated PEoLC services involving the NHS, primary care, hospices, and local authorities, significant inconsistencies remain. **Only 40% of ICBs have electronic care records in place to ensure coordinated delivery of care plans**.[13] This lack of integration leads to fragmented care, with access to services varying widely by setting, geographical location, social deprivation, and minority groups.

Out-of-hours care is particularly variable. While some areas demonstrate good practice in providing access to advice, urgent visits, medication, equipment, and care, others lack some or all of these essential services. For example, 40% of acute hospitals do not meet the NICE 2004[14] requirement for seven-day face-to-face SPC services, and a third of community areas lack 24/7 specialist telephone advice for SPC.

These disparities highlight the urgent need for a co-ordinated, national approach to palliative care commissioning to ensure dignity, equity, and compassion for all.

Recommendation 5: A national strategy to address the gaps in guidance, data collection, service delivery and integration to ensure that every individual, has access to compassionate, high-quality palliative and end-of-life care when they need it most.

Why the 2016 Specialist Palliative Care Commissioning Guidance is Inadequate

The Specialist Palliative Care: Commissioning Guidance (NHS England, 2016)[16] provides a framework for commissioning palliative care but falls short as a comprehensive service specification.
Key shortcomings include:

- **Lack of Detail**: It offers high-level recommendations but lacks detailed, standardised service specifications, such as 24/7 access to advice or medication, leading to inconsistent provision.
- **Non-Mandatory:** The guidance is not legally binding, resulting in variable implementation and no obligation to meet critical standards like round-the-clock care.
- **Inequitable Access**: It fails to address disparities in access for underserved groups, such as those in rural areas, deprived communities, or with non-cancer diagnoses.
- **Workforce and Funding Gaps**: There is no clear guidance on workforce planning, training, or sustainable funding models, despite chronic shortages and underfunding.
- **No Data Framework**: The absence of national data collection or performance metrics makes it impossible to assess service effectiveness or identify gaps.
- **Outdated**: Published in 2016, it does not reflect recent developments, such as community-based care, digital health, virtual wards/ hospital at home models or the Ambitions for Palliative and End-of-Life Care framework.
- **Poor Integration**: It lacks guidance on integrating palliative care with primary, acute, and social care, leading to fragmented and poorly coordinated services.
- **No Public Education**: The document ignores the need for public awareness campaigns to address widespread misconceptions about palliative care.

In summary, while the **guidance provides a starting point, its lack of detail is a barrier to implementation.**

Of Note (regarding children and young people):

The Specialist Palliative and End of Life Care Services for Children and Young People: Service Specification (NHS England, January 2023)[17] also provides a framework for delivering palliative care to children and young people (CYP) but has the same significant limitations.

While it outlines broad principles, it lacks detailed implementation guidance, mandatory requirements, and a clear funding model, leading to potential inconsistencies in service delivery. It does not adequately address workforce challenges, such as shortages and training needs, or ensure equitable access for underserved groups, including those in rural areas or from minority backgrounds. Additionally, the document fails to provide standardised data collection or performance metrics, making it difficult to assess service effectiveness or identify gaps in care. Furthermore, the specification overlooks critical areas such as family support and transition to adult services.

A revised approach is needed to address these gaps and deliver person-centred care that meets the diverse needs of this vulnerable population.

Settings
Palliative care is unique in that it needs to be integrated throughout healthcare in all settings. This includes specialist inpatient units, hospital and community settings, including care homes.

Specialist Inpatient units

Some patients require inpatient care in Consultant-led inpatient units because of complex needs that cannot easily be managed in other settings. These are based in either hospices or hospital settings, delivered by the NHS or independent/charitable sector. Inpatient units should be able to admit and manage patients 24 hours, seven days a week.

Hospices

There is variability in what hospices provide. There is **no formal definition or service specification for 'hospice' and what a hospice provides**. There, however, is a definition of Specialist Palliative Care (SPC). Some hospices are SPC units, others are more generalist looking after their local dying patients, with variability in-between. **On average hospices are 37% commissioned across England**[15] and this incorporates all types of hospice. Thus, there is confusion within the ICBs about what exactly is being provided.

Because hospices are predominantly charity funded this creates innate bias in the system, as a key incentive is fund-raising to maintain their services. This creates inequality throughout the system, as well funded hospices are often serving the higher socio-economic populations as their source of income. It is why there is inequitable access to hospice services as they are not fully integrated into the healthcare ecosystem. **The APM would endorse clear service specifications of hospices and being 100% funded as an integrated part of the NHS**.

Hospital Specialist Inpatient palliative care units

There is a mix with some Trusts (especially in Scotland) providing SPC in-patient beds. The vast majority of hospitals do not provide inpatient SPC beds and those that do the bed provision varies dramatically, with some located within or adjacent to hospitals. Funding models also differ—some rely on charitable support, while others receive varying levels of commissioned funding. In times of high hospital demand, some SPC beds are used for non-palliative patients, while others remain fully ringfenced. Staffing models also vary, with some units employing dedicated palliative care nurses and others managed within general nursing teams. **The APM advocates for clear service specifications for SPC inpatient beds and supports full 100% NHS funding to ensure their integration into the healthcare system.**

Hospital Liaison Service

Specialist palliative care nurses supported by SAS and consultants and the wider multiprofessional team supporting hospital teams to look after patients in a hospital setting. Hospital SPC liaison services are predominantly funded by NHS Trusts. Whilst this ensures a degree of equitability, **it is heavily under resourced** and inconsistent, particularly in relation to out-of-hours delivery particularly in the context of rising demand for palliative care services. Indeed, not all hospitals have access to regular hospital liaison service.

Funding for 7-Day Face-to-Face SPC Services in Hospitals

Patients with palliative care needs require timely, expert interventions, regardless of the day of the week. However, **many hospital SPC liaison services operate on a weekday-only basis, leaving patients without access to specialist care over weekends and out of hours**. This gap often leads to unnecessary hospital admissions, poorer patient outcomes, and increased strain on acute services.

Supportive Care

Supportive care emerged from palliative care in the early 2000's and is primarily integrated within major oncological centres. It focuses on improving the quality of life for patients undergoing cancer treatment by managing symptoms, side effects, and treatment-related complications. Unlike traditional palliative care, which often supports patients with advanced or life-limiting conditions, **supportive care is also provided alongside curative treatments**. It includes pain and symptom management, nutritional support, psychological care, and rehabilitation to help patients tolerate and complete their therapy.

Early Supportive Care (ESC) has been shown to significantly improve outcomes for patients with advanced cancers, particularly in lung, upper gastrointestinal (GI), and haematological cancers. ESC focuses on symptom management, psychological support, and advance care planning, delivered alongside active treatment. However, the benefits of ESC should not be limited to cancer patients. ESC is not readily available in most hospitals and is often limited to availability in a few of the larger centres.

NACEL[18]

Data from the **National Audit of Care at the End of Life (NACEL)** is an audit for generalist palliative care more so than SPC, in hospital settings. It reveals significant variations in access to SPC, with patients from minority ethnic groups 40% less likely to receive SPC compared to their white counterparts. Access to SPC also showed variability, only **37% had 24/7 access**, leading to gaps in symptom management and decision-making support outside of standard working hours. Only **54% of bereaved individuals** felt they had received sufficient emotional support from hospital staff. Additionally, only **56% of hospitals** reported having formal bereavement support services available, highlighting an area in need of improvement.

Community Palliative Care

Specialist palliative care nurses supported by consultants and the wider multiprofessional team liaise between primary care and patients. **Patients and professionals should be able to access advice and urgent assessment 24 hours a day, 7 days a week**. This includes newer models of unplanned care, such as virtual wards/ hospital at home teams. Many specialist palliative care community services are run by hospices / charitable sector and this creates similar inequities as with inpatient hospice services above.

There are many providers of services that have developed in an unplanned way leading to areas with overlapping of services and some areas which lack provision. This creates inequities and difficulties for patients in accessing services when they need them. **The APM would endorse establishing 'Single Points' of access for end of life care in the community both for professionals and the patients.**

As outlined in the introduction, hospitals predominate the cost of care in the last year of life, and part of this reason is the **current funding models are not adequate to support a shift to community**. There is not enough capacity for the current population to be appropriately cared for in the community. A shift to community will need an expansion in workforce of generalist and specialist palliative care services.

Recommendation 6: Service specifications are required for specialist inpatient palliative care beds (and hospices), community and hospital palliative care services and that all are accessible 24 hours a day, 7 days a week with clear outcome measures
Recommendation 7: Core specialist palliative care services should be fully available and integrated on the NHS with 100% funding. Charitable income should be used to supplement core NHS provision.
Recommendation 8: A healthcare professional led Single Point of Access for SPC services should co-ordinate access for service users.

Nursing Homes

There is a paucity of SPC services in Nursing homes in most regions, yet it is becoming the commonest place of death in the next decade. There are occasional local Palliative and end of life care teams allocated to nursing homes, but the sector as a whole is under-resourced regarding its SPC provision. This need urgent assessment as nursing homes are often forgotten in the health and social care provision of palliative care both for generalists and SPC.

Compassionate Communities

Population measures are crucial to develop community resilience and support self-care. Compassionate communities play a vital role in supporting end-of-life care by fostering social networks and reducing isolation for patients and their families. As with other palliative care initiatives, they are inconsistent across the country.

Recommendation 9: A wider look at social care for those in their last year of life, focusing on increased SPC for Nursing homes and Independent funding for community projects such as compassionate communities

Generalist Palliative Care

As stated earlier in this document, this document is mainly focused on SPC, but this is not to underestimate the vital role of all healthcare professionals who care for patients at their end of life. Generalist and SPC are interdependent and symbiotic for a common purpose of best end of life care.

Generalist palliative care is delivered by all health care professionals but primarily **GPs, district nurses, hospital teams, carers and nursing home staff**. The significant under-resourcing of generalist palliative care needs to be addressed with urgency, and it is vital that all healthcare professionals are **trained, and supported appropriately** to ensure best possible experience of care and service utilisation. **40% of hospital inpatients in their last year of life might have been cared for elsewhere** with improved community services.[2]

There is insufficient capacity to deliver Palliative and End of life care to meet NICE standards both in terms of access and quality. About 75% of people who die require palliative care and only 50% of those are currently receiving SPC.[19,20,21,22]

Workforce Challenges

The Palliative care workforce is under significant strain, with shortages of both generalist and specialist staff. The APM/ Marie Curie report (2021)[23] highlights that only 50% of NHS Trusts meet the recommended ratio of SPC consultants to population.

The 2022 Kings College London, Cicely Saunders Institute report on palliative care workforce shortages highlighted a 25% shortfall in specialist palliative care nurses and consultants, underscoring the need for urgent investment.[24] **There needs a clear workforce plan for SPC in line with population and location needs.**

Prioritising SPC Training and Increasing Specialist Numbers

A well-trained workforce is the backbone of effective palliative care. Prioritising SPC within medical and nursing training and increasing specialist training numbers will help bridge the workforce gap, ensuring that expertise in pain and symptom management, psychosocial support, and end-of-life decision-making is readily available to patients. Given the population distribution increase, this is urgent.

Benchmarking Workforce Levels

Establishing clear benchmarks for SPC staffing, including consultants, nurses, and allied health professionals, based on population and location needs.

Updating the 2012 Commissioning Guidance for SPC[25]

The current commissioning guidance must be updated to reflect contemporary needs. Establishing clear, mandated ratios for SPC consultants and clinical nurse specialists (CNSs) per 100 hospital beds and community populations will create consistency in service provision and ensure equity of access across regions.

Recommendation 10: SPC workforce benchmarking, planning, commissioning and funding is urgently required

Teaching and leadership

It is worth noting that in addition to clinical work, SPC teams provide leadership, resource and direction for all services, both in the ethos of palliative care and upholding the best generalist palliative care, through teaching and being held as the exemplar of excellent palliative care.

All SPC teams provide teaching, training, support, quality improvement work throughout the sector and under-resource of SPC translates as a less supported and less effective generalist palliative care.

Equity and equality

Studies show that Black and Asian patients in the UK face significant barriers to specialist palliative care, leading to lower referral rates and poorer symptom management compared to White patients[26]. Ethnic minority patients are **up to 25% less likely to receive home-based palliative care** and **more likely to die in hospital**, despite preferences for community-based care. Key barriers include **language difficulties, cultural differences in attitudes toward palliative care, and mistrust of healthcare.**

Recommendation 11: Equality of access and equity of provision to all ethnicities needs to be monitored and addressed through-out the system.

Conclusion

The Commission on Palliative Care presents a crucial opportunity to reshape and strengthen palliative and end-of-life care, ensuring it meets the needs of an ageing population with increasingly complex conditions. **The evidence highlights an urgent need for a fully integrated, properly funded, and equitably accessible system**—one that guarantees both specialist and generalist palliative care across all settings within the NHS.

Despite the legal duty on ICBs to provide palliative care, critical gaps persist in specialist palliative care workforce capacity, funding allocation, and service coordination. These shortcomings continue to drive inequities in access, unnecessary hospital admissions, and unmet patient needs. To address these challenges, **the full statutory funding of specialist palliative care must be a priority.**

A national service specification is essential to define clear standards for provision, including workforce requirements across inpatient/hospices, community settings, and hospitals. Sustainable, ring-fenced commissioning, is needed to ensure specialist palliative care is available consistently, 24/7, in all settings. Recognising the importance of earlier integration of specialist palliative care is equally vital, enabling patients to maintain the best possible quality of life for as long as possible. Strong clinical leadership must be embedded at the heart of care delivery, quality improvement, and strategic development to drive meaningful change.

At the same time, strengthening generalist palliative care within primary care, community nursing, and hospital services is imperative. All healthcare professionals must be adequately trained and resourced to provide compassionate, high-quality care to those nearing the end of life.

With a coordinated and well-funded approach, the UK can build a system where everyone, regardless of diagnosis, location, or background, has access to the care and support they need when they need it most.

Please provide your name and email below if you would be prepared to give oral evidence or attend one of the round tables:

Please contact office@compleat-online.co.uk or Dr Matthew Doré (Honorary Secretary) matthew.dore@nihospice.org and we would be happy to provide verbal evidence.

Appendix - *Recommendations*

Recommendation 1: Integration of Specialist Palliative Care into the NHS (starting with integration into the NHS Long-Term Plan)

Recommendation 2: Clear specification and monitoring of palliative care services including specialist palliative care (SPC) for accurate commissioning purposes, whilst aiming for 100% funding of SPC

Recommendation 3: Expansion of Specialist Palliative Care workforce and funding to match population and location needs

Recommendation 4: The APM urges the Commission to hold commissioners (ICBs) responsible and accountable for delivering on this obligation for both generalist services and specialist and to provide clear guidance on minimum and appropriate service standards, specifications and metrics.

Recommendation 5: A national strategy to address the gaps in guidance, data collection, service delivery and integration to ensure that every individual, has access to compassionate, high-quality palliative and end-of-life care when they need it most.

Recommendation 6: Service specifications are required for specialist inpatient palliative care beds (and hospices), community and hospital palliative care services and that all are accessible 24 hours a day, 7 days a week with clear outcome measures.

Recommendation 7: Core specialist palliative care services should be fully available and integrated on the NHS with 100% funding. Charitable income should be used to supplement core NHS provision.

Recommendation 8: A healthcare professional led Single Point of Access for SPC services should co-ordinate access for service users.

Recommendation 9: A wider look at social care for those in their last year of life, focusing on increased SPC for Nursing homes and Independent funding for community projects such as compassionate communities

Recommendation 10: SPC workforce benchmarking, planning, commissioning and funding is urgently required

Recommendation 11: Equality of access and equity of provision to all ethnicities needs to be monitored and addressed through-out the system.

Thematic chart

Recommendation	Description
Integration of Specialist Palliative Care	Formal inclusion in NHS Long-Term Plan to ensure prioritisation and funding.
Clear Service Specifications for Palliative Care	Standardised commissioning framework with 100% statutory funding.
Expansion of SPC Workforce	Increased recruitment, training, and funding to match population needs.
National Palliative Care Strategy	Comprehensive strategy to guide commissioning and service provision.
ICB Accountability	Holding Integrated Care Boards responsible for delivering palliative care services.
Hospice Funding Reform	Standardised commissioning framework with 100% statutory funding for SPC
Community-Based Palliative Care	Investment in district nursing, primary care, and 7-day community services.
Equity in Access	Addressing disparities in palliative care access across ethnicity and socioeconomic status.
Hospital SPC Expansion	7-day face-to-face SPC services in hospitals to improve care and reduce admissions.
Workforce Planning	Benchmarking and structured workforce expansion to meet demand.

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