

Health Scrutiny Inquiry Pack – Palliative and End of Life Care

Health Scrutiny Committees (HSCs) play a vital role in scrutinising and shaping local health services, and many already consider issues affecting people at the end of life as part of their wider work programme.

Marie Curie has developed this resource to support HSCs that may wish to examine Palliative and End of Life Care (PEOLC) available to their local population in more depth. It provides practical guidance on how HSCs can plan and deliver an effective inquiry, drawing on their powers to convene partners and hear from a wide range of voices. This includes formal powers to request information from relevant NHS bodies and providers and to require attendance at committee meetings where this is needed to support effective scrutiny. Used well, these powers can help committees test how local services are meeting population need and make informed recommendations for improvement.

The aim is to make it easier for HSCs to scope, plan and undertake meaningful scrutiny that can lead to real improvements for people living with a terminal illness and those who care for them.

1. Context - End of life care in the UK is broken

Whether or not people of all ages can die with dignity – able to access the care and support they need, financially secure and able to meet their material needs, and in the place of their own choosing – is a significant marker of a civilised society. But the reality for too many people today falls far short of what we all hope for and should expect.

End of life care in the UK is broken. Every year, almost one in three people at the end of life do not receive the care they need¹. Dying people suffer avoidable pain and trauma because access to end of life care is inconsistent and unequal². There are significant gaps in end of life care in all parts of the UK today – gaps which are both geographical and which reflect inequities in access to services for people living in poverty, people from ethnically minoritised groups, and a number of other groups.

For many, the end of life is marked by crisis, avoidable hospital admissions and a struggle to access the care needed to die in their place of choice. Too many people struggle to access the

¹ Marie Curie (2026) *Measuring unmet need for palliative care*

² Marie Curie (2024) *Time to care: Findings from a nationally representative survey of experiences at the end of life in England and Wales*

right services in complex, fragmented healthcare systems at a time when they are at their most vulnerable.

In particular, there is a real lack of out of hours care in many parts of the country³. Terminal illness does not respect the clock. The health of a person living at home with an advanced illness can deteriorate suddenly at any time – day or night, during the week or at the weekend. Pain and other symptoms may suddenly worsen. Patients and their carers in this situation need to be able to urgently access support, but we know in too many cases they feel they have nowhere to turn. Many people often have no choice but to call 999, endure distressing ambulance journeys and spend their precious final hours in hospital, which is traumatising for them and their families, and expensive for the NHS. In England, 61% of those who die each year currently use an ambulance in their last three months, and over half visit A&E.

Despite most people expressing a preference to die at home, hospital is the most common place of death. This is because in many areas care isn't available to enable them to fulfil their wish, with too many nurses, GPs and community pharmacists not receiving appropriate training about the needs of people at the end of life. Many people with a terminal illness also experience significant delays in having the assessment and funding put in place for the Fast-Track Continuing Healthcare they need in order to be discharged from hospital or remain in their own homes. This results in many people having to spend their final days and weeks in hospital.

Meanwhile, the cost-of-living crisis continues to have a huge impact on people with a terminal illness, with poverty affecting more than 100,000 people each year at the end of their lives⁴. Many people will have experienced poverty throughout their lives and continue to experience it as they reach the end of life – for many others, however, the often devastating financial impact of terminal illness is what drives them into poverty. A combination of falling income and additional costs (the cost of travel to appointments, medications, and especially higher energy bills) – can drive even families who were previously financially stable into poverty.

Nine in ten of us will require palliative care at the end of our lives. Yet, PEOLC isn't a core NHS service. Government and the NHS fund only around one third of end of life care in the UK, the rest falling to charities who are themselves struggling with rising demand and costs. Although Integrated Care Boards have a legal duty to commission palliative care services which meet the needs of their local population, too many are failing to prioritise PEOLC in their plans and strategies⁵.

Unless we fix this now, more people will go without the right care because:

- Demand is rising fast. The UK population is growing and more of us are living longer, often in ill health. By 2048, an additional 150,000 people across the UK every year will need end of life care.

³ Marie Curie (2022) *Mind the gaps: understanding and improving out-of-hours care for people with advanced illness and their informal carers*

⁴ Marie Curie (2025) *Dying in Poverty 2025 Deaths in poverty and fuel poverty – and what needs to change*

⁵ Marie Curie (2023) *Survey Report: Exploring how Integrated Care Systems are responding to the Health and Care Act 2022*

- Pressure on budgets is increasing too. As well as grappling with growing demand, NHS and care provider budgets are under pressure from the continued cost of living crisis, including higher operating and staff costs.
- Current funding models are failing to keep people out of hospital. Public expenditure on healthcare for people in the final year of life is heavily skewed towards hospital care rather than community-based care. Reducing spend on expensive hospital care will enable us to support more people at home and in the community.

2. Available evidence to support local scrutiny of PEOLC

A range of national and local data sources are available to help you understand how well PEOLC is meeting need in your area, how this is likely to change over time and where there may be gaps or inequities in provision.

The following sources may be particularly useful in helping Committees to scope their inquiry, identify lines of questioning and hold system partners to account.

National data sets

- *Deaths registered in England and Wales: 2024 (ONS)*: Contains a breakdown of the number of deaths by each local authority area.
- *Death projections for local authorities (ONS)*: Contains projections of deaths each year up to 2047 by local authority area.
- *Fingertips end of life profiles (DHSC)*: Provide an overview across multiple geographies in England (including at local authority and ICB level) to support commissioning and planning of local services. They cover various indicators including: place of death and emergency admissions at the end of life.
- *Quality and Outcomes Framework (NHSE)*: Contains data on the number of people on palliative care registers in an area, which can help to help understand how the quality of primary care services can impact outcomes.

Marie Curie research evidence

- *Marie Curie local data packs*: These packs bring together key local indicators on PEOLC. HSCs can use them to understand need, demand and inequalities in their area. They can support scrutiny members to identify local pressure points, compare patterns with national trends and develop focused questions for system partners.
- *Measuring unmet need for palliative care (2026)*: Provides a robust, evidence-based picture of unmet need for PEoLC across England, helping scrutiny members understand both the scale of the challenge and where systems may be falling short. Drawing on national survey data and new research, it defines "unmet need" as a combination of

unaddressed symptoms and insufficient access to support, particularly from primary care, and estimates that around one in three people die with these needs unmet, with clear inequalities linked to factors such as financial hardship and complexity of illness. Alongside quantifying the issue, the report sets out practical implications for service design - highlighting gaps in access, coordination and out-of-hours care - and offers a framework that local systems can use to assess demand, identify underserved groups, and scope targeted improvements in PEOLC provision.

- *Time to care: Findings from a nationally representative survey of experiences at the end of life in England and Wales (2024)*: Demonstrates that end of life experience remains highly variable and often inadequate, characterised by overstretched services, poor coordination, and late recognition of palliative needs. Many people experience frequent hospital use and difficulties accessing timely community care, with family and friends taking on a significant and often unsupported caregiving role that carries emotional and financial impacts. The findings also show clear inequalities, leaving many patients and carers feeling unprepared, unsupported, and let down, underscoring the need for more coordinated, equitable, and well-resourced PEOLC systems.
- *Mind the gaps: understanding and improving out-of-hours care for people with advanced illness and their informal carers (2022)*: Highlights systemic gaps in out-of-hours end of life care. The report shows that people and carers often struggle to access timely advice, medication, or coordinated support outside normal hours, leading to distress, unmanaged symptoms, and increased reliance on emergency services. This raises important questions about how effectively local systems are commissioning and integrating 24/7 palliative care and whether there is a clear, responsive pathway for patients and carers when needs arise at night or weekends. Strengthening out-of-hours provision therefore becomes a critical test of whether local end of life care systems are truly person-centred, equitable, and fit for rising demand.
- *Dying in Poverty: Deaths in poverty and fuel poverty – and what needs to change (2025)*: Research commissioned by Marie Curie and conducted by the University of Loughborough which found that over 100,000 people a year die in poverty in the UK (about 1 in 6 deaths) due to rising costs and gaps in the benefits system.⁶ We have poverty rates at the end of life for each local authority area across England – these can be accessed [here](#).
- *Dying in Poverty: Briefing for Local Government*: Sets out the role that local authorities can play in easing the financial burden at the end of life, including prioritising terminally ill people for support via discretionary schemes such as Council Tax Support and the Crisis and Resilience Fund.
- *Shaping support for people at the end of life: A guide for local government (2025)*: A practical guide for local government highlighting the crucial role councils can play in improving PEOLC.

Committees may also wish to draw on local JSNAs and ICB strategic plans to triangulate these data sources and test how far system plans align with current and future need.

3. Who to involve

Engaging a wide range of partners and people with lived experience will help the Committee build a rounded picture of how the PEOLC system is performing locally, where the pressure points are, and which changes are most likely to improve outcomes in your local context. Where possible, we would recommend inviting stakeholders who can speak to strategy, commissioning and funding, service delivery, patient experience, and inequalities (including access for underserved groups and those living in poverty).

- **System leaders and commissioners** (ICB; local authority adult social care; Health & Wellbeing Board)
- **Specialist palliative care** (hospice and specialist community services)
- **Primary and community care** (GPs/PCNs; community nursing; community services).
- **Hospital and discharge partners** (acute and community trusts; discharge teams; continuing healthcare/fast-track leads).
- **Social care providers** (care homes; homecare/domiciliary care; workforce and quality leads).
- **Acute services** (ambulance trust, urgent care/A&E).
- **People and communities** (people with lived experience, carers and bereaved people; VCSE groups supporting underserved communities).

4. Suggested lines of enquiry

Need, demand and inequalities

- How well does current PEOLC provision meet existing demand locally?
- How does the ICB plan to meet growing need for PEOLC as our population ages and more people live with complex conditions?
- How do system partners use data to understand local population need and address inequalities and inequities in access to PEOLC?

Strategy, leadership and accountability

- How has the ICB's Integrated Needs Assessment identified current and future palliative and end of life care needs within its population?
- How is the ICB preparing for the forthcoming Modern Service Framework, and what changes does it expect to make to local palliative and end of life care in response?
- How will local neighbourhood health approaches help ensure people approaching the end of life can access timely, coordinated support in the community and avoid unnecessary crisis care or hospital admission?

Commissioning and funding

- How is the ICB using the findings of its Integrated Needs Assessment to inform strategic commissioning decisions, service development priorities and investment in palliative and end of life care?

- How does the ICB assess whether current investment in PEOLC is sufficient to meet local need, including rising demand and unmet need?
- How does the ICB work with hospice, community and voluntary sector providers to develop sustainable PEOLC funding arrangements?
- To what extent is current PEOLC spend weighted towards crisis and hospital care rather than earlier, community-based support, and how is the ICB seeking to shift this balance?

Early identification and proactive care planning

- What plans are in place locally to enable early identification of palliative care needs?
- How is the system ensuring that people identified as approaching the end of life are offered timely, personalised advance care planning conversations?
- What are system partners doing to reduce late identification, so that fewer people reach crisis point before receiving coordinated support?

Access and co-ordination across settings

- How easy is it for people approaching the end of life, and those caring for them, to access the right support at the right time across different parts of the system?
- How well are PEOLC services coordinated across primary care, community services, hospitals, hospices and social care?
- How well are advance care plans recorded, shared and acted on across settings?
- Where are the main gaps, delays or points of fragmentation in local PEOLC pathways, and what is being done to address them?

Out of hours, urgent and crisis response

- What arrangements are in place locally to ensure people with PEOLC needs can access timely advice and support out of hours?
- Does the ICB have a 24/7 single point of access advice line for PEOLC, accessible to the whole population? How is it funded and promoted to patients/carers and professionals?
- What arrangements are in place locally to provide out-of-hours access to PEOLC medicines? What do community pharmacies report as the main barriers?
- How is the ICB monitoring avoidable ambulance call-outs, emergency admissions and hospital deaths linked to gaps in out-of-hours or crisis PEOLC support?

Workforce, skills and support

- How confident and well supported are generalist staff - including GPs, community nurses, care home staff and domiciliary care workers - to identify, support and care for people approaching the end of life?
- Where are the most significant workforce gaps or pressures in local PEOLC provision, and what impact are they having on access, continuity and quality of care?
- What is the ICB doing with partners to strengthen PEOLC workforce planning, skills development and retention across the system?

Financial insecurity at end of life

- How are people approaching the end of life, and those close to them, being supported to access welfare benefits and other financial help?
- Is the council prioritising terminally ill people for discretionary financial support, including via council tax exemptions and the new Crisis and Resilience Fund?

About us

Marie Curie is the UK's leading end of life charity. We're here for anyone with an illness they're likely to die from, and those close to them. We bring 75 years of experience and leading research to the care we give at home, in our hospices and over the phone. And we push for a better end of life for all by campaigning and sharing research to change the system.

Get in touch to discuss how we can work together: local@mariecurie.org.uk