Marie Curie

Measuring unmet need for palliative care

February 2026

The briefing draws on research conducted as part of the *DUECare Project: Defining and Estimating Unmet Palliative Care Needs in the UK**, funded by Marie Curie. The research was co-led by Dr Anna Bone and Professor Fliss Murtagh and carried out in partnership by the Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation, King's College London, and the Wolfson Palliative Care Research Centre, Hull York Medical School, with contributions from the Clinical Psychology, School of Health in Social Science, University of Edinburgh.

The briefing also includes personal testimony from people whose loved ones experienced unmet need at the end of their lives.

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Executive summary

HOW we care for dying people is a key marker of a civilised society. It shows our true sense of community and fellowship. But as shown so sharply by the research reported in this briefing, too often we are letting dying people down.

Shockingly this new research shows that nearly one in three people in England die with unmet need for palliative care. That means dying with both significant levels of unaddressed symptoms and concerns *and* inadequate access to sufficient care from GP services.

That represents around 170,000 people in England each year – or nearly one every three minutes. And we know that there are profound inequities in access to palliative and end of life care, with people from different groups and with different diagnoses having widely differing experiences.

Every single one of us deserves to have our preferences on the care and support we receive listened to with respect. But the needs, interests and preferences of most people at the end of life are deeply neglected both in public discourse and public policy.

As a result, for far too many people, their end of life experience is not where they want to be, with family and friends close – but stuck in the back of an ambulance or in an emergency department following an unnecessary admission to hospital.

For far too many people, end of life experience means dying alone – without anyone to care for or support them.

And without urgent action, these problems are only going to grow in coming years. It is estimated that in the next 25 years, unmet need for palliative care is expected to rise by 23% – around 40,000 more people in 2050 compared to 2025.

It doesn't have to be this way.

Every person living with terminal illness deserves to receive the right care, at the right time, in the right place. That's why we are calling on the Government to ensure that:

- **everyone has access to care at the right time** – by guaranteeing a 24/7 single point of access for palliative care services in every part of the country
- **everyone has care available in a place close to them** – by recommitting to palliative care being fully embedded in every neighbourhood health service in England
- **everyone can receive quality support from all healthcare providers** – by making palliative and end of life care a compulsory part of training for all health and care professionals, including those in primary care and emergency medical services.

Introduction

THE need for palliative and end of life care (PEoLC) is rising as our population ages. Over the next ten years in England, more than 5.75 million people will die, and the vast majority will have palliative and end of life care needs. By identifying these needs, we can help ensure holistic care and support is co-ordinated according to what people want and that their preferences, priorities and values are met, ensuring better symptom management, quality of life, and informed care choices.

Many dying people are still missing out on the care and support they need. This is not only distressing for dying individuals and those who love and care for them, but also creates extra unnecessary strain across health and care services. Access to PEoLC has been shown to be effective at reducing emergency admissions, ambulance use, and unwanted hospital deaths. Yet people continue to miss out on even basic access to support closer to home through primary care services in their final months and weeks of life. And we know that groups who experience marginalisation throughout their lives continue to face this at the end of life.

It is vital that service providers have a comprehensive understanding of palliative care needs and how to manage these effectively for every person they care for. But understanding the level of need for palliative and end of life care across the population is also vital, to ensure we commission enough services, of the right types and in the right locations, to meet these needs. To date, it has been challenging to get an accurate picture of how many people don't have their needs met, which groups within the population may be disproportionately affected, and how this might change in future. This insight is crucial to enable the equitable design and delivery of services so that everyone gets the right care, in the right place, at the right time.

In this briefing, we set out a refined definition of 'unmet need', which means we can both measure and better understand this issue. Using this approach, we've calculated current estimates of unmet need and projected future increases at population level in England. We also provide recommendations and actions for how unmet need can be addressed.

What is unmet need for palliative care and how can we measure it?

What is unmet need for palliative care?

To work out how many people have unmet need for palliative care, first we need to define what it is. This is not, however, an easy task, as each person has both their own unique set of needs, based on what most matters to them, and different perceptions of how well these needs are – or are not – met.

The research included work to develop a shared definition of unmet palliative care need based on workshop discussions with people affected by terminal illness and the health and care professionals who work with them.

Workshop participants identified and ranked several elements that describe unmet palliative care need. The elements prioritised most focused on service delivery, quality and access, for example:

- lack of timely and holistic assessment of symptoms or suffering
- inability to access services needed
- lack of coordination and continuity of care.

The workshop participants also identified:

- lack of recognition of palliative care needs
- absence of a single point of contact for support (including out-of-hours care)
- lack of timely follow up to address symptoms and concerns
- insufficient skilled and competent care
- not being treated with respect, dignity, and empathy.[1]

Lack of timely and holistic assessment of symptoms or suffering received the highest total score, and **inability to access services needed** appeared most frequently in the top 10 (74%).

Based on these findings, the researchers established the following short definition for unmet need for palliative care:

> **Unmet palliative care needs are present when a person with life-limiting illness has symptoms, psychosocial concerns, or care requirements that are not adequately addressed through available services, with inability to access or receive person-centred care.**

How can we best measure unmet need for palliative care?

The definition of unmet need above was used to analyse the results of a nationally representative survey of 1,194 bereaved family carers, to find the number and proportion of people with unmet need for palliative care. The survey was commissioned by Marie Curie and conducted by the ONS across England and Wales between May and November 2023.[2]

When analysing this survey, someone was considered to have unmet need for palliative care if they had both:

- unaddressed symptoms and concerns, **and**
- lacked sufficient access to help from GP services.

These were measured in the following ways.

Unaddressed symptoms and concerns

This is based on the proportion of people with unaddressed symptoms (physical and psychological) and concerns in the last week of life using the Integrated Palliative Care Outcome Scale (IPOS).[3]

IPOS is an internationally used assessment tool that enables patients to self-report their experience of common symptoms and issues. A proxy version is available when patients are unable to answer questions themselves.

For the purposes of this research someone is considered to have 'unaddressed symptoms and concerns' if bereaved former carers reported that they had more than half the maximum possible total score across all 17 IPOS items (≥34 out of 68) in their final week of life.

Lack of sufficient access to help from GP services

This is based on the proportion of people lacking sufficient access to help from GP services to resolve symptoms and concerns using bereaved former carers' responses to the survey question: "In the last three months before they died, overall, do you feel they got as much help as needed from GPs?"[4]

Sharon explains the impact of not receiving sufficient support from GP services

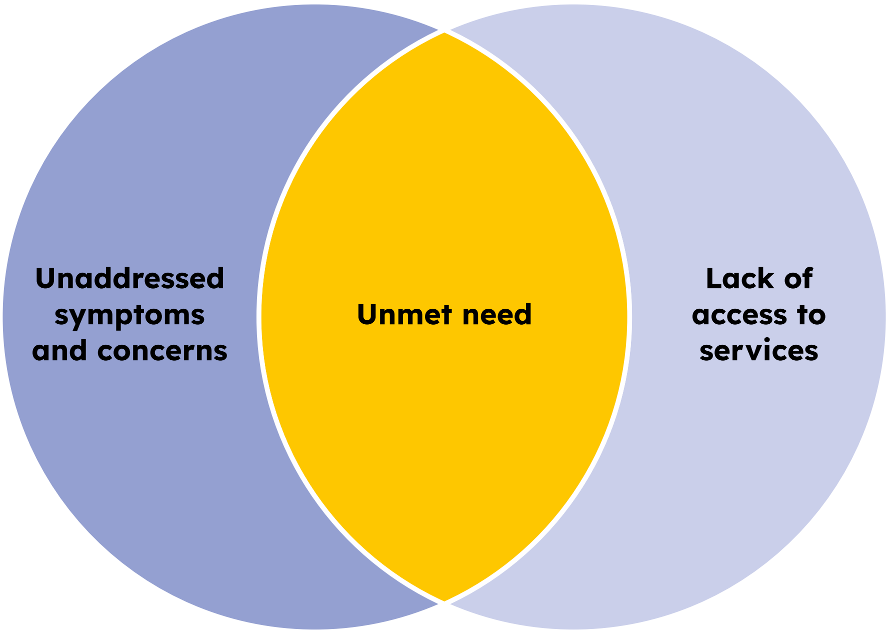
"We didn't have much support from the GP at all. Because of where we live in the Fens, we're about an hour away from hospitals in each direction, and any support was all in the hospitals. There was nothing local for us. I wasn't driving at the time and Kevin couldn't drive because of the fits, so it was really difficult to access any support. We fell through the cracks and had to fight for everything.

"The last three days I stayed in the room with him and lay there with him overnight while he was in a hospital bed. We weren't offered overnight care at all, so it was all down to me. I did two nights by myself. Our son was on standby to come and help, but he lives 40 minutes away and he was at work, so it really was just the two of us. The anticipation of him having a seizure, or if you need to get hold of a GP and you can't get hold of them, was awful. The District Nurses were great and they were on the end of the phone, but it does feel quite lonely. It was so frightening.

"There was one weekend towards the end when the District Nurse said that we wouldn't have enough drugs for the weekend. When I phoned the GP on the Friday to order more, I had an argument with the receptionist. That's the thing that I remember now that really makes me upset. I was arguing with this receptionist saying, 'My husband is dying, I need more drugs' while I was sitting next to him, and he's listening. He was unconscious by then, but I don't know if he could hear me or not. That was awful. The issue was that the receptionist was saying that he did have enough medication, but the District Nurse had said he needed more. In the end, the District Nurse called and argued too. Then we had to get it home from the doctor – you can't get it delivered because it's too quick – so my 80-year-old neighbour had to go and get it for me."

Combining unaddressed symptoms and concerns, and lack of access to GP services

The new approach to measuring unmet need for palliative care combines the two measures above. So, having **both** unaddressed symptoms and concerns **and** lacking sufficient access to help from GP services (using the approach to survey analysis set out above) means someone has unmet need for palliative care.



How many people have unmet need for palliative care?

USING the method above, it was possible to calculate the number of respondents reporting that their loved ones had unmet need for palliative care in the survey sample. It was then possible to estimate the proportion and number of people with unmet need for palliative care in the wider population, using mortality data from the same year as sampled deaths (2022).

This gives us a robust estimate of the number of adults who had unmet need for palliative care in England at population level.[5]

It shows that in 2022 around 248,000 adults (46%) living with terminal illness in England had unaddressed symptoms and concerns at the end of life. Around 245,000 people (46%) had insufficient access to support from GP services at the end of life.

Around 170,000 people in England (32%) had **both** unaddressed symptoms and concerns, **and** lacked sufficient access to help from GP services at the end of life – meeting our definition of unmet need for palliative care. That represents nearly one person dying with unmet need for palliative care every three minutes.

How are different groups affected by unmet need?

We know there are profound inequalities in access to, and experiences of, health and social care services, including palliative care. The analysis shows these inequalities are reflected in unmet need for palliative care.

The findings showed that there is variation in risk of unmet need based on personal characteristics. The data showed no differences between men and women in terms of unmet need, and no differences by ethnicity, likely due to the small number of Black, Asian and other minoritised ethnicity respondents in the sample, comprising over 95% White respondents. However, the findings showed variation in levels of unmet need on the basis of diagnosis, and that people who were 85 or older were less likely to have unmet needs than those in the 65–84 age range. There are many potential factors for these variations that require further research to ensure service providers identify how to improve care.

The findings also show that the risk of unmet need increases for people who

Table 1: Unmet need for palliative care in England

Estimation factor	England (N=536,311)
1. Symptoms and concerns	247,993 (46%)
2. Insufficient primary care provision	244,612 (46%)
3. Unmet need for palliative care (1 and 2)	169,537 (32%)

experience financial difficulty at the end of life. A quarter (25%) of people living comfortably experience unmet need, this increases to almost one third (32%) among people ‘doing alright’ financially and to 36% among those ‘just about getting by or finding things difficult’. This means those who are ‘just about getting by or finding things difficult’ financially experience 45% additional risk of having unmet need compared to those living comfortably.

Risk of unmet need is also greater for those with more complex health problems. The findings show 25% of people with no comorbidities experience unmet need and this increases to 30% for those with one additional condition and to 34% unmet need for those with two additional conditions, or three or more additional conditions. This means that people with one comorbidity experience 19% additional risk of having unmet need than those without comorbidities, and the additional risk is 37% for people with three or more additional comorbidities.

How are levels of unmet need expected to change in the future?

England has a growing and aging population, and as a result, it’s likely that palliative care need will also increase in coming years. Without urgent action to address the problem, unmet need for palliative care is also likely to rise sharply.

Applying the new estimates of unmet need to official mortality projections show that, without additional intervention, around 40,000 more people are likely to face unmet need for palliative care in 2050, compared to 2025 – a total of around 210,000 people per year. **This would represent an increase of 23% over today’s figures.**

Table 2: Projected future unmet need in England

Estimation method	**Number of adults in England**		
	2025	**2050**	**% change**
1. Symptoms and concerns	253,795	307,661	↑21%
2. Insufficient primary care provision	249,453	313,298	↑26%
3. Unmet need for palliative care (1 and 2)	173,320	212,357	↑23%

What can be done to reduce unmet need for palliative care?

WE are already facing unacceptably high levels of unmet need for palliative care in England, and it's clear that without action, many more people will face this in the future. We need to see a range of actions to address this current crisis.

Marie Curie has been calling on the UK government to produce a comprehensive national action plan to address already high levels of unmet need, tackle significant inequalities in access to this vital care, and support the growing numbers of people who will be living with, and dying from, multiple and complex conditions. We welcome the Government's commitment to produce a Modern Service Framework for palliative and end of life care. To successfully tackle rising demand and unmet need, the framework must establish how to ensure care is available:

1. At the right time – addressing the lack of support available out of working hours

Far too many people find that even if they can get support in normal working hours of 9am to 5pm Monday to Friday, the support they need disappears through the night and on the weekends. Often this leaves people with nowhere to turn apart from emergency services.

Clare discusses the challenges of trying to access out of hours support

"I got in touch with them and there was a gentleman that answered and I said: 'Mum needs more medication' and he said: 'we don't work at night' and I was like: 'what do you mean you don't work at night?'. He says they're only there 9 'til 5 and I was going: 'well, what's Plan B then? As my mum needs more pain relief', because he could hear my mum in the background crying and screaming. And I explained the district nurses are here. but that they can't give my mum any more. I offered to fetch a prescription from them, so the nurses could give it. That was a 'no'. I asked if he was a prescriber and he said he was, so I said I could come up and bring him to Mum and then bring him back. Another 'no'. So I asked what I do instead then and his response was 'ring 111'. Three years on, I'm still waiting for that phone call back from the 111 doctor...

"... I can't believe that they would leave somebody in pain because they only work 9 'til 5. That's what I can't get my head around it. Cancer doesn't know nighttime. And there was no Plan B. If they'd got another prescription ready, I could have gone and picked it up and brought it back to the nurses. I mean, at the end of the day, does it really matter that she's having more and more pain relief. She was dying.

"All I know is that my mum was in pain at the end and that should never have happened."

A 24/7, single point of access for terminally ill people, their carers and the health and care professionals working with them, can help make sure people get the support they need, when they need it.

For example, the IMPaCT service in the North West of England improves coordination across palliative care. Two service "hubs" allow patients, carers and healthcare professionals to get help via a 24/7 palliative and end of life care telephone line. As a result, IMPaCT has brought down emergency hospital admissions at the end of life by 13%.

- **The UK Government should commit to every part of the country having a 24/7 single point of access palliative and end of life care telephone advice line, staffed by professionals with specialist palliative care expertise who can provide advice, guidance and support to access local services, available to all people with a terminal illness, their carers and health and care professionals.**

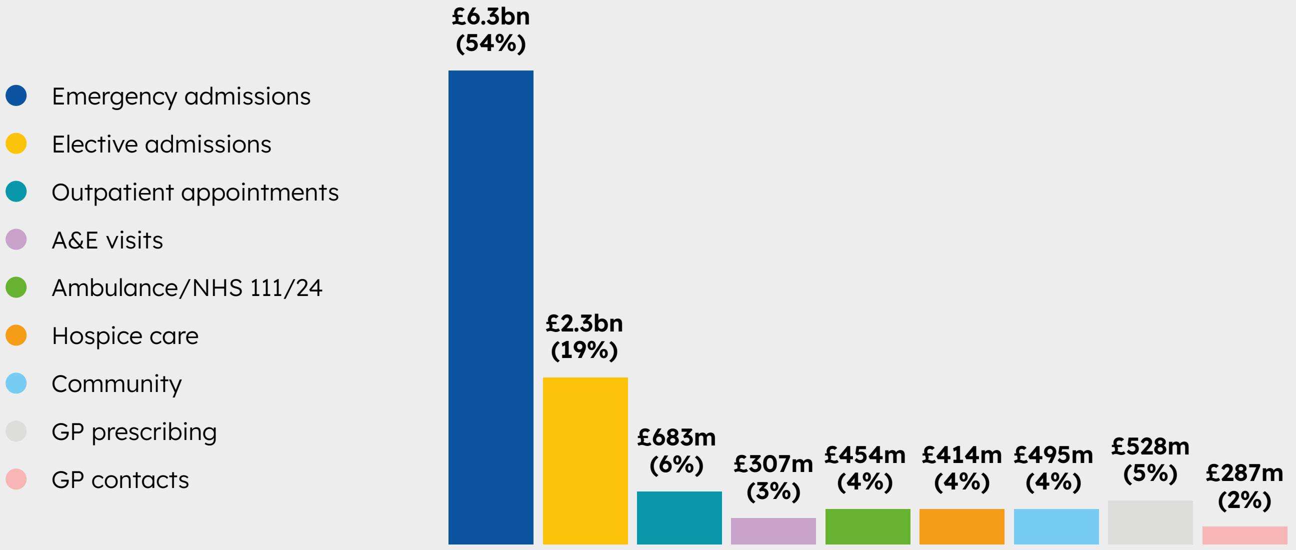
2. In the right place – embedding palliative care in neighbourhood health

The 10 Year Health Plan for England sets out an ambition to shift care from hospital to communities. In no part of the health system is this a more pressing challenge than in end of life care.

Hospital remains the most common place of death in England, with more than two in five people dying there – and 41% of that group dying alone. As a result, of the £11.7 billion spent each year on healthcare support for people in the final year of life across the UK, an incredible £8.6 billion is spent in hospitals.[6]

Yet there is strong evidence that with the right support in place in community settings, more people can be helped to stay out of hospital and die in their own homes instead of calling an ambulance, visiting A&E and having unplanned hospital admissions. A death in hospital is rarely the best place for the patient (or the NHS staff team) and is far more expensive than supporting a death at home or in a care home.

Figure 1. Estimated expenditure on healthcare for people in the last year of life (£11.7 billion)



Source: Public expenditure in the last year of life briefing[7]

We need to shift care closer to home, both to improve access for patients and families and to reduce the significant pressures on emergency and acute services. With this in mind, we welcome the UK Government's commitment to embed palliative care in neighbourhood health services, to bring healthcare closer to people's homes.

- **The UK Government must recommit to palliative care being fully embedded in every neighbourhood health service in England, and support this with upfront funding in order to ensure that this can be delivered.**

3. The right care – ensuring that the palliative care workforce is fit for the future

Palliative and end of life care will not improve on its own. It needs both generalist and specialist workforces with the right skills to improve care in the right ways. Every health and care professional is likely to care for people at the end of life at some point in their career. Palliative and end of life care is not currently a compulsory part of either initial training or continuing professional development for most health and care professionals, leaving many feeling ill-equipped to support people at the end of life in planning, providing and coordinating care.

- **The UK Government should make palliative and end of life care a compulsory part of training for all health and care professionals, including those in primary care and emergency medical services.**

Conclusion

THIS is not the first report to call out the inadequacies that exist in the palliative and end of life care system. The recent palliative care commission and the independent expert panel report paint a stark picture of a system under growing strain, with insufficient recognition of palliative and end of life need, an ill-equipped workforce, and patchy provision of services leading to systemic inequity in the quality of services available and the quality of support received.

Every case in which someone dies with unmet needs is a personal tragedy, the impacts of which can be felt by those who loved them long after they are gone. However, this is the first time in recent years that new research has put a number on just how many people are dying with unmet need for palliative care. The results are shocking, but in truth they aren't surprising. They are the result of persistent lack of prioritisation and chronic underfunding of services, made worse by failure to invest in a workforce that desperately wants to care for people at the end of life but has neither the resources nor the training to do so effectively.

Dying people, their loved ones, and the whole palliative and end of life care system need more than warm words from those with the power to change this situation. The scale of the challenge can no longer be ignored. By taking long overdue action on the findings of this research, and acting to ensure that the right care is provided in the right place and at the right time, the UK Government has the opportunity to make a real, practical difference on an issue that affects us all.

We can't afford to wait any longer.

Appendix 1. UK and devolved nation figures

This briefing set out the findings for England, but the survey covered both England and Wales. A policy briefing for Wales is also available.[8]

How many people in Wales have unmet palliative care need?

The findings indicate that, in total in 2022, around 17,000 people (49%) living with terminal illness in Wales face unaddressed symptoms and concerns at the end of life. Around 15,000 people (43%) have insufficient access to basic primary care services at the end of life.

Around 10,000 people in Wales (29%) have **both** unaddressed symptoms and concerns **and** lack access to basic primary care services at the end of life – and so are considered to have unmet need for palliative care. That represent nearly one person dying with unmet need for palliative care every three minutes.

How are levels of unmet need in Wales expected to change in the future?

Without additional intervention, around 1,500 more people are unlikely to get their palliative care needs met in 2050, compared to 2025 – a total of almost 12,000 people per year. This would represent an increase of 14% over today's figures.

Table 3: Unmet need for palliative care in Wales

Estimation method	Wales (N=35,511)
1. Symptoms and concerns	17,209 (49%)
2. Insufficient primary care provision	15,280 (43%)
3. Unmet need for palliative care (1 and 2)	10,246 (29%)

Table 4: Projected future unmet need in Wales

Estimation method	Number of adults in Wales		
	2025	2050	% change
1. Symptoms and concerns	17,372	20,521	↑18%
2. Insufficient primary care provision	15,430	18,106	↑17%
3. Unmet need for palliative care (1 and 2)	10,393	11,826	↑14%

How many people in the UK have unmet palliative care need?

We have also applied prevalence of unmet need (averaged for England and Wales) to the relevant deaths data for Scotland and Northern Ireland, to arrive at an estimate for unmet need across the UK as a whole.[9]

In total, the findings indicate that across the UK as a whole around 200,000 people are unlikely to get their palliative care needs met each year, or one person every three minutes.

How are levels of unmet need in the UK expected to change in the future?

Without additional intervention, around 44,400 more people are unlikely to get their palliative care needs met in 2050, compared to 2025 – a total of over 250,000 people per year. This would represent an increase of 21% over today's figures.

Table 5: Unmet need for palliative care in the UK

Estimation method	UK (N=651,482)
1. Symptoms and concerns	302,152 (46%)
2. Insufficient primary care provision	294,385 (45%)
3. Unmet need for palliative care (1 and 2)	203,442 (31%)

Table 6: Projected future unmet need in the UK

Estimation method	Number of adults in the UK		
	2025	2050	% change
1. Symptoms and concerns	308,713	372,589	↑21%
2. Insufficient primary care provision	299,881	373,516	↑25%
3. Unmet need for palliative care (1 and 2)	207,792	252,275	↑21%

Endnotes

1. A. E. Bone, M. Diggle, T. Johansson, A. Finucane, K. E. Sleeman, J. M. Davies, I. J. Higginson, L. K. Fraser and F. E. Murtagh (2025) "Coproducing a conceptual understanding of unmet palliative care needs: stakeholder workshops using modified nominal group technique" BMC Palliative Care https://link.springer.com/article/10.1186/s12904-025-01971-4
2. There is a small variation in the reported number of respondents between the Better End of Life Care report and this DUECare study. Better End of Life report included data up to end of September 2023 (1,179 respondents), while this study included data up to end of November 2023 (1,194 respondents)
3. For the purposes of this metric, a cut-off was applied at half the maximum possible total score across all 17 IPOS items (≥34 out of 68) to indicate unmet needs.
4. 'Sometimes', 'No' and 'Did not receive care from them' were coded as having unmet needs.
5. In total 1,194 surveys completed by bereaved family carers by the end of November 2023 (response rate 39.8%). 619 (52%) decedents had lived in England and 575 (48%) in Wales.

   Sampled causes of death from the main conditions considered amenable to palliative care (specialist or non-specialist) using selected ICD-10 codes (which indicate the cause of death)
6. Cummins et al. 2025, Public expenditure in the last year of life Research report (mariecurie.org.uk/document/public-expenditure-in-the-last-year-of-life-report). London (UK): Marie Curie
7. mariecurie.org.uk/document/public-expenditure-in-the-last-year-of-life-briefing
8. mariecurie.org.uk/document/unmet-need-in-wales-report-2026
9. The unweighted average proportions of unmet need found for age- and sex-specific groups in the samples for England and Wales were applied to deaths in Northern Ireland and Scotland that would benefit from palliative care to arrive at whole UK population estimate.

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* This briefing draws on the following: *Defining and measuring unmet palliative care needs* https://pubmed.ncbi.nlm.nih.gov/41652311/, *Coproducing a conceptual understanding of unmet palliative care needs* https://pubmed.ncbi.nlm.nih.gov/41437023/ and *Unmet palliative care needs in England and Wales: population-based estimates and future projections (2025-2050)*

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