



Association for
Palliative Medicine
Of Great Britain and Ireland



Association of Palliative Medicine and Marie Curie survey of palliative care practitioners 2021

The United Kingdom is at a critical moment for improving palliative care. As a result of our ageing population, in twenty years' time there will be 100,000 more people dying each year in the UK – demand for palliative care will increase rapidly, with the number of people dying with a need for palliative care projected to increase by up to 42%.

Everyone deserves the best possible experience during their final illness and at the end of life, but the reality for far too many people falls far short of what we all hope for and should be able to expect. Estimates suggest that while as many as 90% of people who die in the UK may have a need for some specialist or generalist palliative care, only around 50% of people who die actually receive it. [Research by Marie Curie](#) and others indicates that certain groups face particular barriers in access to palliative care, including people who are living in poverty, alone, or with dementia – as well as people with learning disabilities, those who are homeless or in prison, BAME groups and LGBTQ+ people.

The Covid-19 pandemic has been a stress-test for whether our health and care system is meeting the needs of people dying in all settings, with a significant rise in the number of deaths occurring in people's homes and care homes. A recent Marie Curie [survey of carers of people who died at home during pandemic](#) found that 76% felt their loved one did not get all the care and support they needed.

Our survey

In the context of these challenges, Marie Curie and The Association for Palliative Medicine of Great Britain and Ireland (APM) conducted a new survey of palliative care specialists across the UK and Ireland in December 2021 and early January 2022 to explore their experiences of working in end of life care throughout 2021.

The survey was open to members of the Association for Palliative Medicine of Great Britain and Ireland, from various roles in hospital and hospice settings as well as community settings such as consultants, speciality doctors, junior doctors and clinical nurse specialists. Respondents were most likely to practise in hospices (59%) followed by hospitals (47%) and the community (38%).

Fieldwork took place between 15th December 2021 and 5th January 2022 using an online methodology. All APM members were emailed a link to an online survey, of whom 129 practitioners responded.

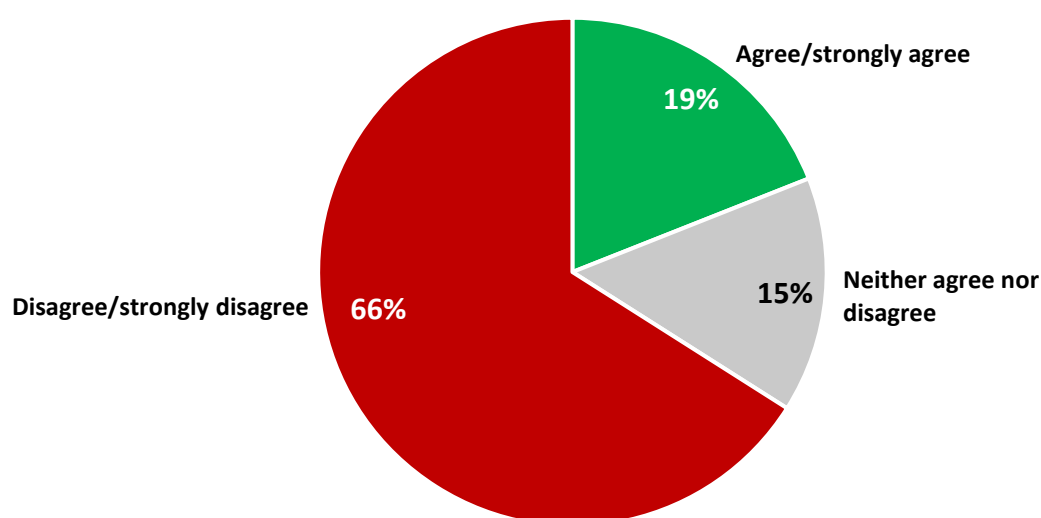
Survey results are rounded to the nearest 1% and excluded any respondents who stated that the question was Not Applicable.

Key Findings

Capacity

Our study found that only 19% of practitioners felt there had been sufficient capacity overall to deliver high-quality specialist palliative and end of life care in their locality in the last year. Two thirds of practitioners (66%) felt there had not been sufficient capacity overall to deliver this as illustrated in the chart below.

Q Over the last twelve months (2021), to what extent to you agree there has been sufficient capacity overall to deliver high-quality specialist palliative and end of life care in your locality?



The results revealed a particular challenge with regard to delivery of specialist palliative care in patients' homes and care homes - contexts which have witnessed a [sustained increase](#) in the number of deaths during the pandemic. Just 12% of practitioners felt that capacity was sufficient in their locality to deliver high quality specialist palliative care in these community settings. Around three quarters (73%) felt there had not been sufficient capacity in these settings, echoing the experiences reported by bereaved carers in our earlier [survey](#).

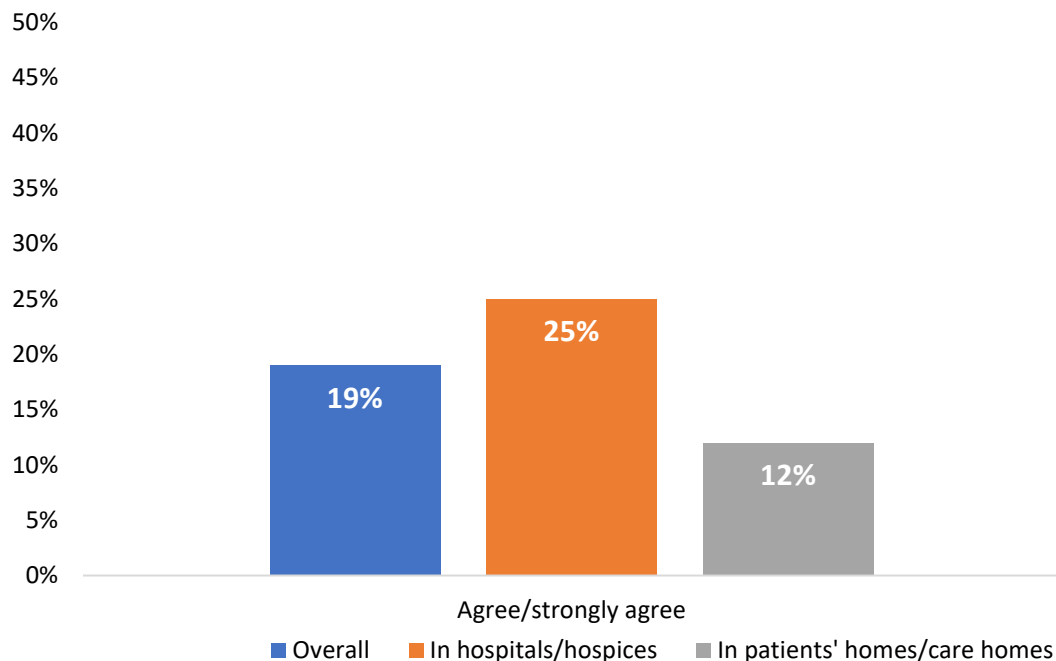
"There has been a big increase in community palliative care need with no increase in resources. Therefore we are spread too thinly and it is difficult to provide high quality care."

"Many patients are missing out, especially the large increased numbers who are in their own homes during COVID either because of hospitals busy with COVID, or because of fear of going to hospital because of COVID and/or isolation from family."

We found that with regard to delivery of specialist palliative care in hospital and hospice settings, views of capacity were slightly more positive. A quarter (25%) of practitioners agreed capacity had been sufficient to deliver high quality specialist care. However, still more than half of practitioners (52%) felt capacity had not been sufficient in these settings.

Graph showing views on sufficient capacity by setting

Q Over the last twelve months (2021), to what extent to you agree there has been sufficient capacity to deliver high-quality specialist palliative and end of life care in your locality...?



Access

Our survey also found issues around patient access to end of life care. Delays throughout the system were widely recognised as obstructing and limiting access. Only 17% of practitioners felt that patients were referred in a timely manner for them to fully benefit from specialist palliative care. In addition, 86% of practitioners had encountered patients presenting as terminal who had had a late diagnosis due to the NHS backlog.

Furthermore, missed opportunities and professional failure to recognise need were seen additional barriers to patients in receiving specialist palliative care. 71% of practitioners expressed a view that professionals were missing opportunities to refer patients, and 72% believed professionals were not recognising when patients need specialist palliative care.

Inadequate staff resourcing, expertise, and retention, alongside service closures due to infection and COVID restrictions, were spontaneously identified as key factors impacting access as illustrated in the quotes below.

"I believe referrals were impacted by professionals lacking in time, a reduction in face to face assessments, and high turnover of staff leading to a workforce with limited knowledge of locally available services."

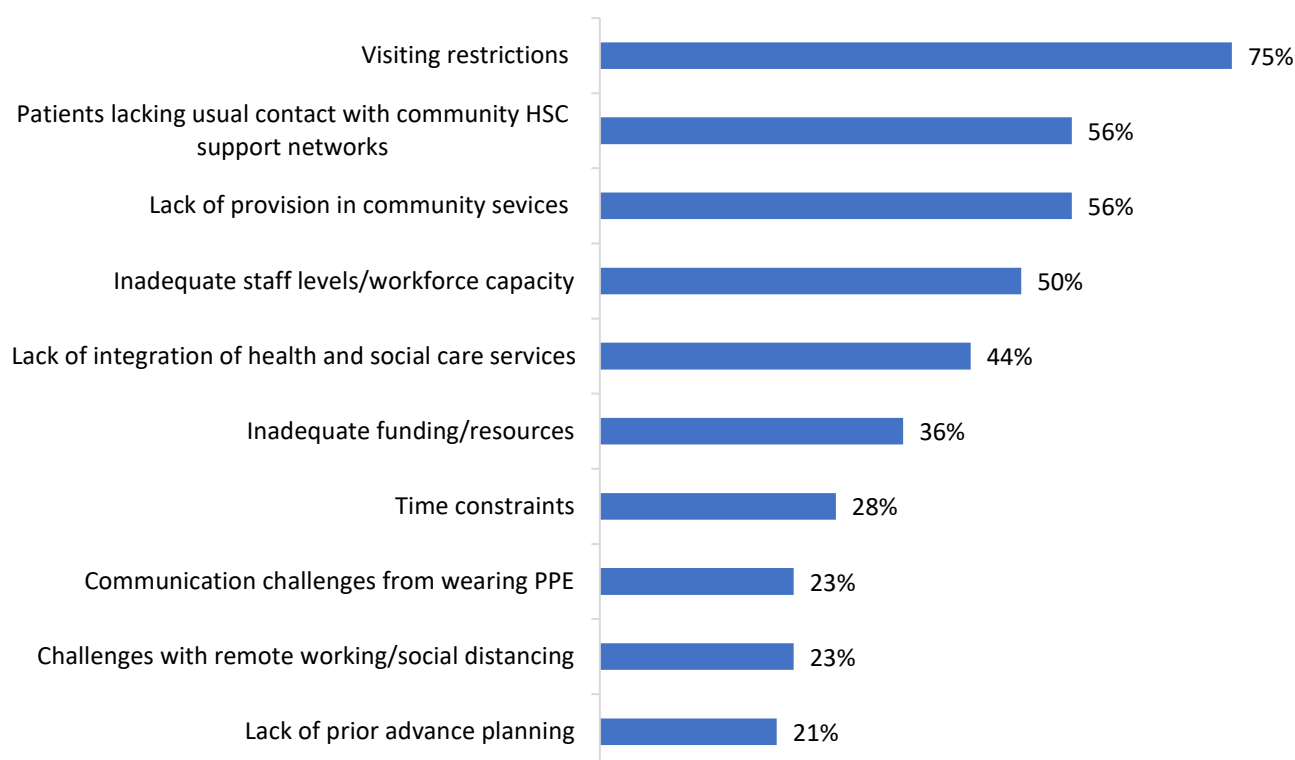
"Due to isolation and sickness, capacity to deliver specialist palliative care has been massively lacking, with loss of 7-day service in both Hospital and community, and the Hospices frequently closed due to infection control or staffing issues."

Key challenges

Our research found that visiting restrictions, reduced access to community-based services and support networks, and inadequate workforce capacity were the biggest perceived challenges to practitioners' ability to provide high-quality specialist palliative and end of life care.

The graph below shows the ten factors which practitioners were most likely to say had had a large impact on delivering high quality palliative care in the last year.

Top 10 challenges



Resourcing of specialist palliative care, also emerged as a key issue, with 36% of respondents highlighting this as having a large impact. It is also notable that 44% of respondents highlighted the challenges caused by poor integration of health and social care – an important issue which Integrated Care Systems are intended to address.

“Specialist palliative care is chronically under resourced and designed to provide a reactive rather than a proactive service to patients. District nursing services and carer support is extremely limited and so patients have not had the generalist support needed for good end of life and palliative care.”

“The volume and complexity of patients has clearly increased with the same or less resource, meaning that resources have had to be focused and not available as broadly.”

Experiences of unpaid carers

In addition to the growing pressures on professionals, there was a consensus that unpaid carers had also faced unprecedented pressure. 91% of practitioners felt that unpaid carers (friends and family)

had accepted more emotional and physical burdens in caring for their loved one than was the case prior to the pandemic.

More than half who responded (57%) said they strongly agreed this had been the case, while just 2% said they disagreed.

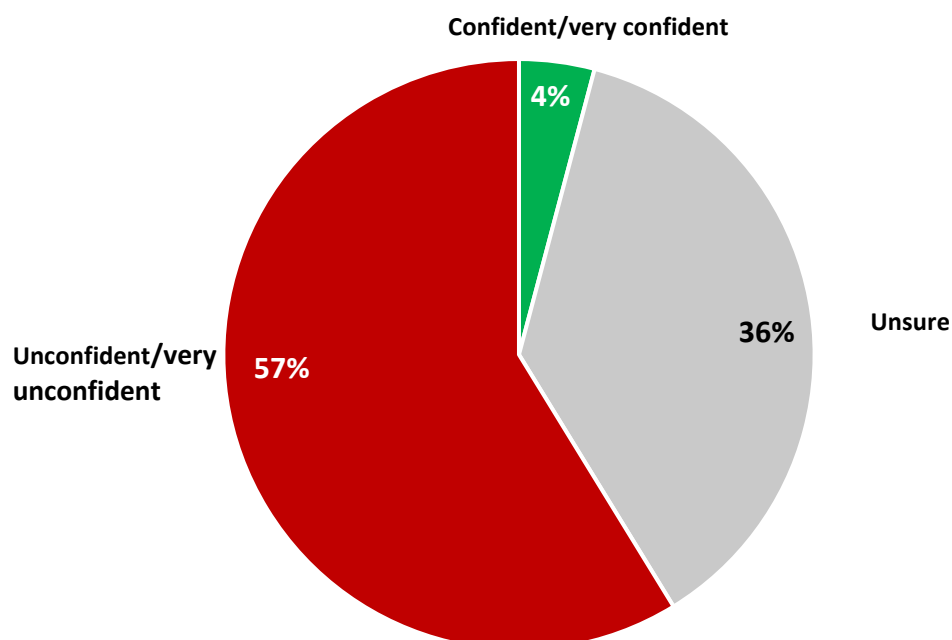
10-year outlook

Our study found that current deficiencies in capacity to deliver high quality specialist care were reflected in practitioners' levels of confidence about the future. An overwhelming majority of practitioners (93%) felt either unconfident or unsure that there will be sufficient capacity to deliver high-quality specialist palliative care in ten years' time, with 57% saying they were unconfident or very unconfident about this.

"I am the Clinical Director of specialist palliative care services across two areas and the pressure on both teams has been incredible and burnout is imminent. Something needs to be done urgently to prevent a significant event and complete failure to deliver services in all settings. At the moment, it looks very bleak..."

"There are just not enough staff in either the NHS, social care or independent sectors to be able to look after people. It is only going to get worse, and I'm an optimist!"

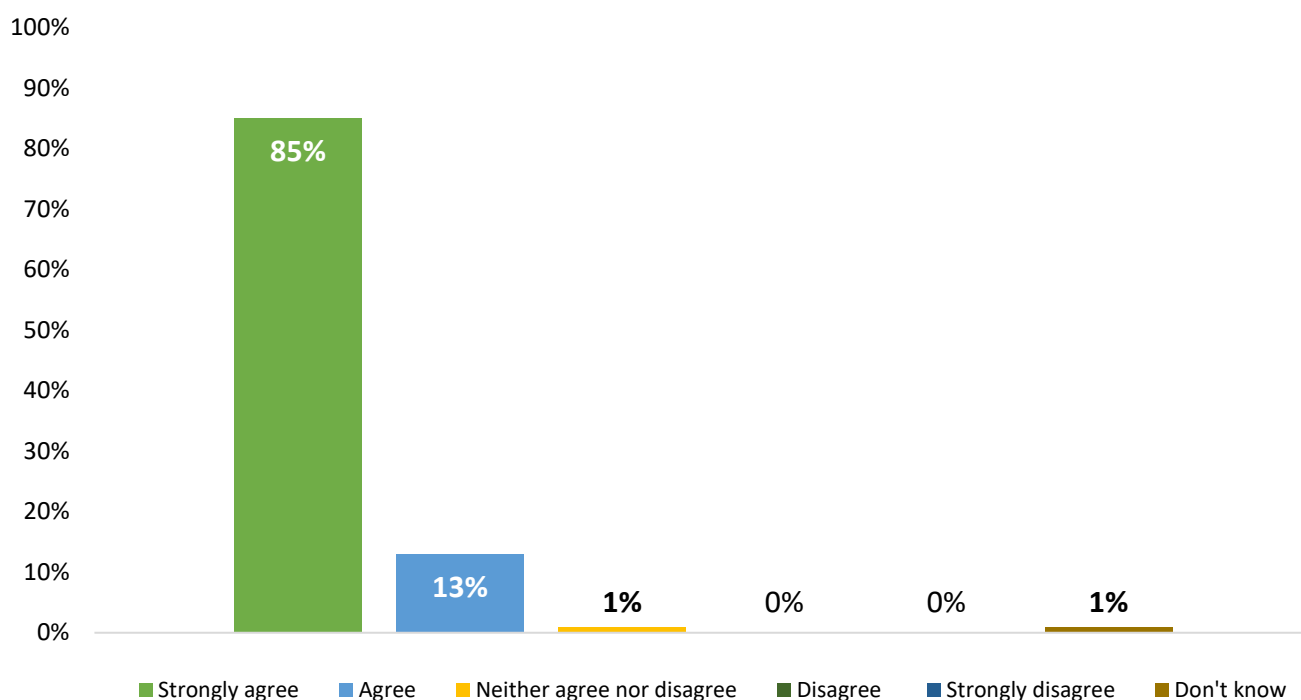
Q How confident are you that there will be sufficient capacity to delivery high-quality specialist palliative care in 10 years' time?



Commissioning of specialist palliative services

Our research found that 98% of practitioners believe commissioning specialist palliative services should be compulsory in every part of the UK, with 85% saying they strongly agreed with this statement.

Q To what extent do you agree with the following statement: Commissioning specialist palliative services should be compulsory in every part of the UK?



Conclusion

Marie Curie and the Association of Palliative Medicine believe that there should be a fundamental right to access palliative and end of life care and support services for everyone who needs it. Our new research highlights the significant current gaps in capacity to provide these specialist services to a high quality, a failure to reach all patients who could benefit from them at the optimal time, and huge uncertainty about the future of palliative care among those who work in this important area.

The research shows that practitioners themselves overwhelmingly agree that commissioning these services should be compulsory in every part of the UK.

The Health and Care Bill is a unique and welcome opportunity for our health and care system to learn lessons from the Covid-19 pandemic, prepare for a future of growing demand for specialist palliative care, prevent future crises and help ensure that nobody misses out on the care and support they and their families need during life limiting illness, both now and in the future.

Clause 16 of the Health and Care Bill provides Integrated Care Boards with duties to commission hospital and other health services for those persons for whom they are responsible. Several specific services are highlighted in Clause 16, with a duty for commissioners to ensure they are provided,

such as maternity, dental and ophthalmic services; however, the clause fails to mention specialist palliative care as currently drafted.

Marie Curie and the Association of Palliative Medicine are calling to amend Clause 16 to provide Integrated Care Boards with a duty to commission palliative care.

Improving the availability of specialist palliative care services will have a number of benefits to people at the end of life, including increased compliance with people's end of life wishes and reduced care costs. Ensuring proper palliative care is available to people nearing the end of life has been shown to also reduce pressure on NHS services, including by reducing hospital bed days for people at the end of life and reducing unplanned hospital admissions.

Reducing unplanned and potentially avoidable hospital admissions would not only be less distressing for patients and their families, but would also reduce pressure on NHS hospitals – with around 5.5 million bed days among people in the last year of life in England, we estimate that the total cost of these admissions is more than £1.2bn¹.

By 2030, one in five people in the UK will be aged over 65 and the number of people receiving palliative care services is projected to increase from 47% of all deaths to 66% over the next decade. At the same time, the nature of care need is also changing – with an increasing proportion of people dying at home or in a care home – which will lead to growing pressure on primary care, social care and communities.

In this context, there are growing concerns about the sustainability of the palliative care sector and its funding model. Approximately two-thirds of expenditure on palliative care services comes from charitable fundraising and one-third from the NHS and other statutory sources; improving the availability of commissioned services will provide the sector with financial stability, supporting it to plan for the future.

About the proposed amendment

Clause 16 of the Bill provides Integrated Care Boards with duties to commission hospital and other health services for those persons for whom they are responsible. It includes duties to provide dental services, nursing and ambulance services, and services or facilities for the care of pregnant women, women who are breastfeeding and young children.

We recommend amending this clause to introduce a requirement for integrated care boards to arrange for the provision of specialist palliative care services.

These commissioned services should include:

- Providing support in every setting including private homes, care homes, hospitals, hospices and other community settings;
- Including hospice and other palliative care beds when required, including admission on an urgent basis;
- Making specialist palliative care advice available on a 24/7 basis;
- Ensuring the right, skilled workforce, equipment and medication is available to deliver this care;
- Providing support by telephone from specialist healthcare professionals;
- Ensuring a point of contact is available for people with palliative and end of life care needs if their usual source of support is not accessible; and
- Ensuring systems are in place to share information about the person's needs with all professionals involved in their care, provided they give consent for this.

¹ Based on NICE estimate of care in an acute bed costing on average £222 per day.

- Supporting advance care planning development in all services to ensure patients are able to have open conversations about their needs and concerns.

A similar amendment was discussed in the Commons Committee stage but was not pressed to a vote.

For more information on the issues covered in this briefing, please contact Mark Jackson or Ruth Driscoll via parliament@mariecurie.org.uk

[Marie Curie](#) is the leader in end of life experience in the UK. We work hard to provide a better life for people living with a terminal illness and their families. We offer expert care across the UK in people's own homes and in our nine hospices. Last year, we supported more than 50,000 people across the UK at the end of their lives.

Our free information and support services give expert care, guidance and support to families so they can have something that really matters to them – time to create special moments together.

We are the largest charitable funder of palliative and end of life care research in the UK and campaign inside and outside Parliament for the policy changes needed to deliver the best possible end of life experience for all.

[The Association of Palliative Medicine](#) of Great Britain and Ireland (APM) is the world's largest representative body for doctors practicing or interested in Palliative Medicine, with a growing membership of over 1,000.

We seek to create a future where all people with life-limiting and life-threatening illnesses live as well as possible for the duration of their natural lives and in which no one need die in distress or discomfort for lack of access to the best palliative care.

We work in strategic alliance with those who can contribute to achieving our vision, supporting our values and delivering our aims.