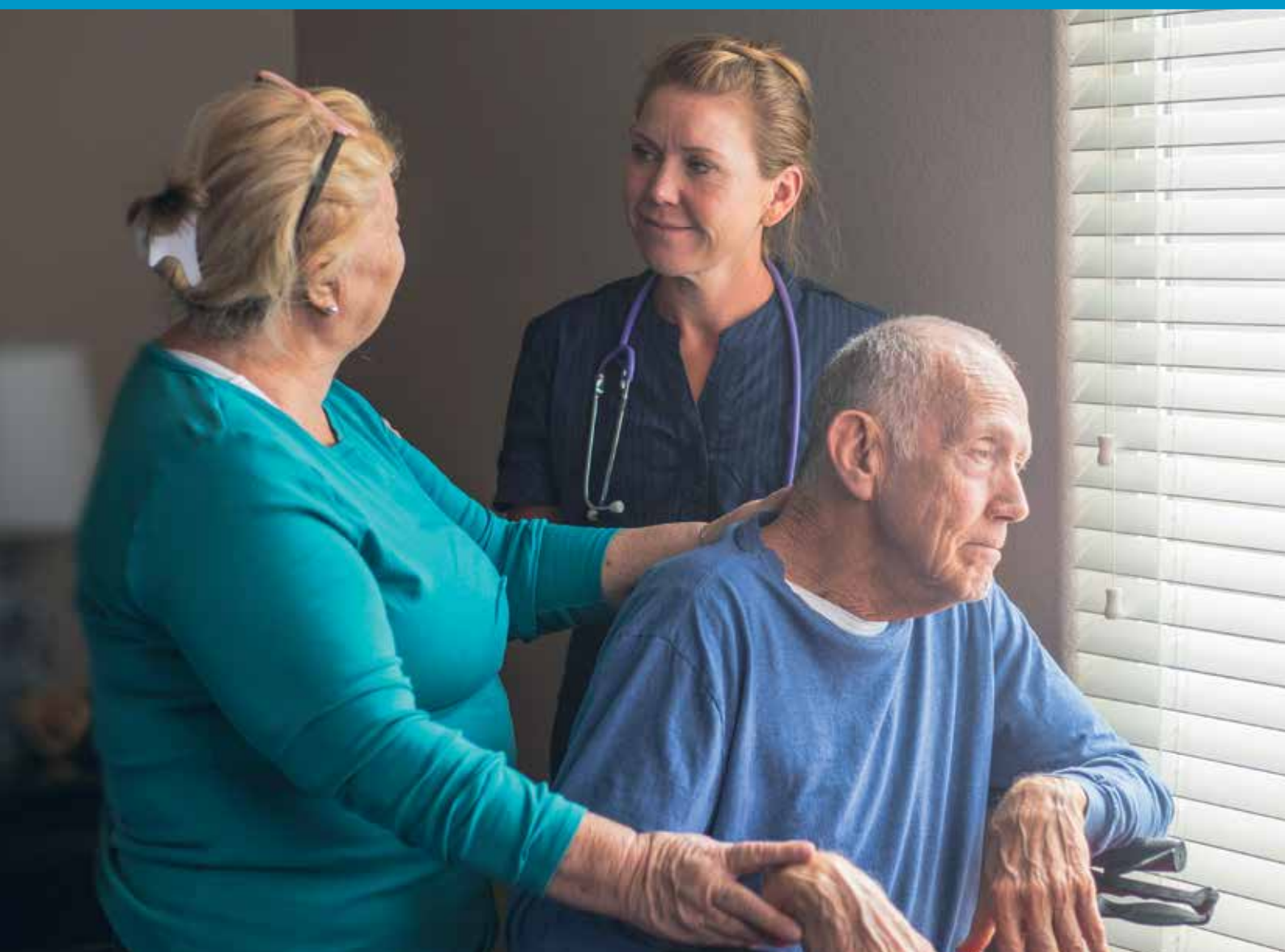




All-Party Parliamentary Group
Hospice and End of Life Care

Government funding for hospices



February 2024

Supported by  **hospice**UK

Contents

Executive Summary	3
The value of the hospice sector	4
Recommendations	5
Introduction	6
1. The hospice funding model in England	8
1.1 The funding model	8
1.2 Funding streams	8
1.3 Reliance on charitable donations	9
2. Impact of the new ICS system and statutory requirement	11
2.1 Changing system, changing relationships	11
2.2 Profile of hospices and end of life care	11
2.3 Understanding of palliative and end of life care	13
2.4 Decision making	14
3. Shortcomings of the funding model in England	16
3.1 Funding for hospices and ICBs	16
3.2 Unjustified variation	17
3.3 Depreciation in the value of contracts	19
4. External pressures on funding	21
4.1 Cost of living crisis	21
4.2 Changes in population need	22
5. Alternatives to the current model	24
6. Reflections on the hospice funding model in Scotland, Wales and Northern Ireland	26
Conclusion	28
References	31

Disclaimer

The evidence submitted to this inquiry highlighted the importance and sensitivity of relationships between hospices and their Integrated Care Boards. For this reason, we have taken the decision to anonymise evidence which relates to specific relationships and remove footnotes in these instances.

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This Report was researched and funded by Hospice UK.

Executive Summary

Despite the introduction of a legal requirement for Integrated Care Boards (ICBs) to commission palliative and end of life care, ICB commissioning of hospice services is currently not fit for purpose. As a result, the services hospices provide for dying people and their families and the value they provide to the health system is at risk.

Hospices provide essential palliative and end of life to 300,000 people every year.¹ Often, they support some of the most complex deaths, experienced by people with very high need. This specialist care prevents people who are dying from the trauma of inappropriate transfers, spending hours in A+E or feeling stuck on a hospital ward. Many hospices also train care workers and NHS staff to support people who are dying in other sectors. However, the full benefits of an integrated and sustainably funded hospice sector are currently unrealised.

The UK Government must produce a national plan to ensure the right funding flows to hospices. This should include measures that support ICBs with their commissioning decisions now to ensure a level playing field and help evolve a truly sustainable hospice funding model in the longer term.

ICBs must commit to delivering their statutory requirement and start by placing hospices on multi-year contracts, paying the full cost of commissioned clinical services and offering hospices the same annual increases as NHS services.

Despite the legal requirement for ICBs to commission palliative and end of life care in the 2022 Health and Care Act, this APPG found that the funding hospices receive from ICBs varies significantly across the country. ICB adult hospice spending per head of population ranged from £10.33 to just 23p per head of population.² ICB children’s hospice funding also varied hugely from an average of £511 to £28 per child with a life limiting condition.³

“The care provided by the hospice was very different, it helped shape our grieving of our son and ultimately was lifesaving. I cannot imagine a different scenario where we did not have that time with our son as a family.”

Parent/Carer with lived experience.⁴

Evidence also revealed that hospices are not being commissioned on a level playing field with NHS services as ICB funding often does not reflect the cost of clinical care. Over the last two years, 28% of ICBs provided annual increases to hospice contracts that were below increases offered to NHS services in their area.⁵

The need for palliative care is projected to increase by 25% by 2048.⁶ The contribution of hospices is both vital to meeting this need and to ensure the NHS and social care have the capacity to prevent and treat disease. We hope that our recommendations will support both national Government and ICBs to make the necessary reforms to fully realise the benefits of the hospice sector and maintain the vital role they play in our wider healthcare system.

The value of the hospice sector

Hospices have an important role within the health and care system and in their local communities. They provide essential care to those at the end of their lives and provide their loved ones with crucial support through such hard times.

The core clinical services that hospices provide, both in their inpatient units and the community, are an indispensable part of palliative and end-of-life care in the UK. These services reduce pressures on the wider health and care system and keep people out of A&E or hospital when it is not best for them to be there. Without hospices, the complex care they provide would have to be provided by the NHS, at high cost.

Specialist hospice teams also provide support to NHS and social care colleagues across the system. For example, by training care home workers in how to support people who are dying or offering advice and guidance to hospital teams.

"He wanted to stay at home, so we spoke to Douglas Macmillan Hospice and they were just amazing. Words can't express how grateful I am to them. They said, 'the hospice has got a bed for you - if you want it, it's yours.' After hearing his wishes, they set it all up: they got us a hospital bed downstairs, they put everything in place. Within 48 hours, my front room had been transformed... It was absolutely phenomenal. They were just brilliant."

Lived experience shared with Hospice UK.⁷

Hospices are pillars of their local community, bringing people together in order to support each other and raise money for services that have helped them and so many of their neighbours. Charitable fundraising also allows hospices to raise money to deliver enhanced services, such as counselling, bereavement support and activities, that are hugely appreciated by the people they serve and benefit the wider system.

Recommendations

For the UK Government to:

- produce a national plan to ensure the right funding flows to hospices. This should include measures that support ICBs with their commissioning decisions now and help evolve a truly sustainable hospice funding model in the longer term.
- conduct or commission a piece of work to understand the costs of providing different models of palliative and end of life care with the long-term aim of developing reference costs on palliative and end of life care that can be used by commissioners.
- develop national quality standards and agreed outcome measures, which commissioners can use to assess the quality of the services they are commissioning.
- set out a national minimum standard for the level of provision of palliative and end of life care that must be provided within all ICBs.
- address the immediate pressures of paying increased staffing costs for hospices by providing emergency funding and thoroughly consider the impacts on the hospice sector within the NHS pay review process each year.
- ringfence the £25 million provided by the Children's Hospice Grant to ensure it reaches its intended destination and commit to maintaining this grant for the next five years.

For NHSE to:

- undertake a proactive programme of support to ICBs on how to interpret the NHSE guidance on commissioning palliative and end of life care and what they are required to commission in their area.
- hold ICBs accountable for their commissioning of palliative and end of life care by ensuring Joint Forward Plans deliver the priorities of Integrated Care Strategies based on local need assessments.
- provide guidance to ICBs on how to commission VCSEs (Voluntary, Community and Social Enterprise), including a timeline for commissioning decisions to ensure negotiations are timely, transparent and proportionate.

For ICBs to:

- ensure the prominence of palliative and end of life care in the Integrated Care Partnership's joint strategic needs assessment and that this informs their commissioning decisions.
- ensure that hospices are on multi-year contracts.
- ensure uplifts to hospice contracts are equitable with uplifts received by NHS-run services and other hospices in the area.
- ensure voluntary sector partners have a named senior contact within the ICB who has responsibility for commissioning in their area.

Introduction

Hospices are a critical part of the health and care system. They provide care and support to 300,000 people a year across the UK and work across the system to train and support health and care workers.⁸

There has long been concern over the sustainability of the hospice funding model. On average, two thirds of hospice income is charitable, raised through fundraising such as charity shops and marathons.⁹ This often leaves hospices in a precarious position, never knowing whether they will have enough funding to continue to deliver their services.

For hospices and other providers of palliative and end of life care, the introduction of a new statutory requirement to commission palliative care in the 2022 Health and Care Act is a welcome opportunity to address unequal and unsustainable hospice funding.¹⁰ The Act specified that;

“An integrated care board must arrange for the provision of the following to such extent as it considers necessary to meet the reasonable requirements of the people for whom it has responsibility...services or facilities for palliative care as the board considers are appropriate.”¹¹

The APPG launched this inquiry into government funding for hospices in order to understand what impact the statutory requirement has had on hospice funding in England, whether ICBs are fulfilling their new statutory obligations, and what needs to change to build a health and care system fit for the future.

After launching this inquiry in August 2023, the APPG received over 80 pieces of written evidence from hospices across England, Integrated Care Boards, NHSE and national organisations with perspectives on palliative and end of life care. The APPG also received evidence from hospices in Scotland, Wales and Northern Ireland about the funding models in their countries.

The APPG held two oral evidence sessions in Parliament to dig deeper into the key questions surrounding the sustainability of hospice funding. The evidence received provided vital insight into funding for the hospice sector and its impact on the support people receive at the end of their lives.

This report includes the inquiry's key findings and recommendations to National Government, NHSE and local authorities to ensure hospices can contribute to a system where everyone who needs palliative and end of life care receives it.



1. The hospice funding model in England

1.1: The funding model

Hospices sit at the intersection between health and social care and provide a variety of services depending on the needs of their local community.

The majority of care hospices provide is in the community. This includes work by specialist teams of doctors, nurses and allied health professionals.¹² Community support allows people to stay at home when this is their wish, prevents unnecessary admissions to hospital and supports timely and safe discharge. Many hospices also have in patient units (IPUs), which typically support patients with the most complex care needs who require focused and specialist support.¹³

Many hospices will also provide outpatient clinical support and advice, such as fatigue management and breathlessness clinics, and other support services such as counselling, respite care and bereavement support.¹⁴

Hospice teams also share their specialist knowledge with NHS and social care workers to support them to provide care to patients with palliative and end of life care needs.

“Our palliative care team could not do their jobs effectively and support people in our communities without our local hospices.”

Mid Yorkshire Teaching NHS Trust.¹⁵

The hospice funding model is unique in the health and care system. Hospices provide essential health and care services to people with terminal and life limiting conditions, yet this is only partly funded by Government.

Hospice UK has found that hospices receive roughly one third of their income through government.¹⁶ The rest of their income is charitably fundraised.

In evidence submitted to this inquiry, hospices describe the funding system as ‘an anomaly’, and

argue that no other area of the healthcare system relies so heavily on charity.¹⁷ Hospices and end of life care charities state that this funding model is not sufficient, resilient or sustainable.¹⁸

One respondent to this inquiry shared that in their experience, this funding situation was not fully understood by the public, who expect the essential clinical care that hospices provide would be NHS funded in full.¹⁹

1.2: Funding streams

Government funding for hospices comes from multiple sources but the most common route for adult hospices is funding delivered via Integrated Care Boards. Integrated Case Systems (ICSs), local health and care partnerships for 42 geographical areas across England, were established in the 2022 Health and Care Act.²⁰ Within each ICS, an Integrated Care Board (ICB) is responsible for commissioning health and care services, including palliative and end of life care. The majority of government hospice funding is provided by ICBs, which are now required by law to commission sufficient palliative care services for their population.

NHSE also produced statutory and non-statutory guidance to support ICBs in delivering the new requirement. This guidance advises ICBs to take a whole system approach and assess how they deliver against the Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026. It also specifies that ICBs ‘should’ implement a service specification for end of life care, and ensure there is sufficient provision of end of life care to meet population need.²¹

Alongside the money they receive through contracts with their ICB, some hospices receive funding from local authorities, for example at borough level.²² This is often funding for a specific service, for example, where hospices provide domiciliary care services, funding will come from the local authority.

Historically low funding for children’s hospices, led to the introduction of the NHSE Children’s Hospice Grant, which was originally introduced as a Department of Health grant in 2006/7. Children’s hospices in England receive this money directly from the NHSE, rather than from local ICBs. For children’s hospices, it is a vital source of funding within a ‘patchy’ system.²³

The grant makes up a significant portion of government funding for children’s hospices, one hospice reported that the grant they receive makes up 50% of their government funding. In early 2023, NHSE told children’s hospices in England that grant would come to an end that year. This was a significant concern for the hospice sector, until NHSE confirmed the grant will be extended for the year 2024/25 with children’s hospices receiving a collective £25 million.²⁴ The future of the grant beyond April 2025 is unknown and the impact of not receiving this funding for children’s services would be serious.²⁵

Funding also varies depending on the type of service. The Childhood Bereavement Network and National Bereavement Alliance submitted evidence on the bereavement services provided by hospices, which is a significant proportion. Some hospice bereavement services are restricted, for example only available to those who have been bereaved of someone who died in their care. However, increasingly following the pandemic, hospice bereavement services are becoming open to anyone in their area. These services are a vital part of mental health support in the community and can help to prevent people developing complex grief disorder and requiring more acute and ongoing mental health support.²⁶

Under CCGs, hospices received funding for bereavement services from a range of sources. Some had funding from the CCG or local authorities, while some were entirely charitably funded.²⁷

Following the 2022 Health and Care Act, there was debate over the extent that bereavement services were included in the statutory requirement to commission palliative and end of life care. The Commissioning and Investment Framework for Palliative and End of Life Care, which aims to support the requirement states that it is a core requirement to provide assessment of bereaved people and to have referral pathways to sufficient support.²⁸ Emotional and psychological bereavement support services, however, are considered an enhanced service and the framework specifies they should be charitably funded. However, as stated above, bereavement support is often a core part of local mental health support and therefore also requires sustainable funding.²⁹

1.3: Reliance on charitable donations

The hospice sector’s reliance on fundraising for the majority of its income carries huge risk. For example, during the COVID-19 pandemic, many charity shops had to be closed and sporting events cancelled, with serious consequences for hospice finances.³⁰ Other, more common factors that impact funding streams include rises in the cost of living that reduce communities’ ability to give, or unpredictable legacy droughts.³¹ The volatility of this income makes it hard to plan for the future and puts services perpetually at risk.³²

Evidence to the APPG also emphasised how this reliance on donations deepens socio-economic inequalities. Communities in the most economically deprived areas are least likely to be able to donate to their local hospice. As a result, their local hospice may have a lower income than hospices in more affluent areas and its community may have poorer access to services.³³

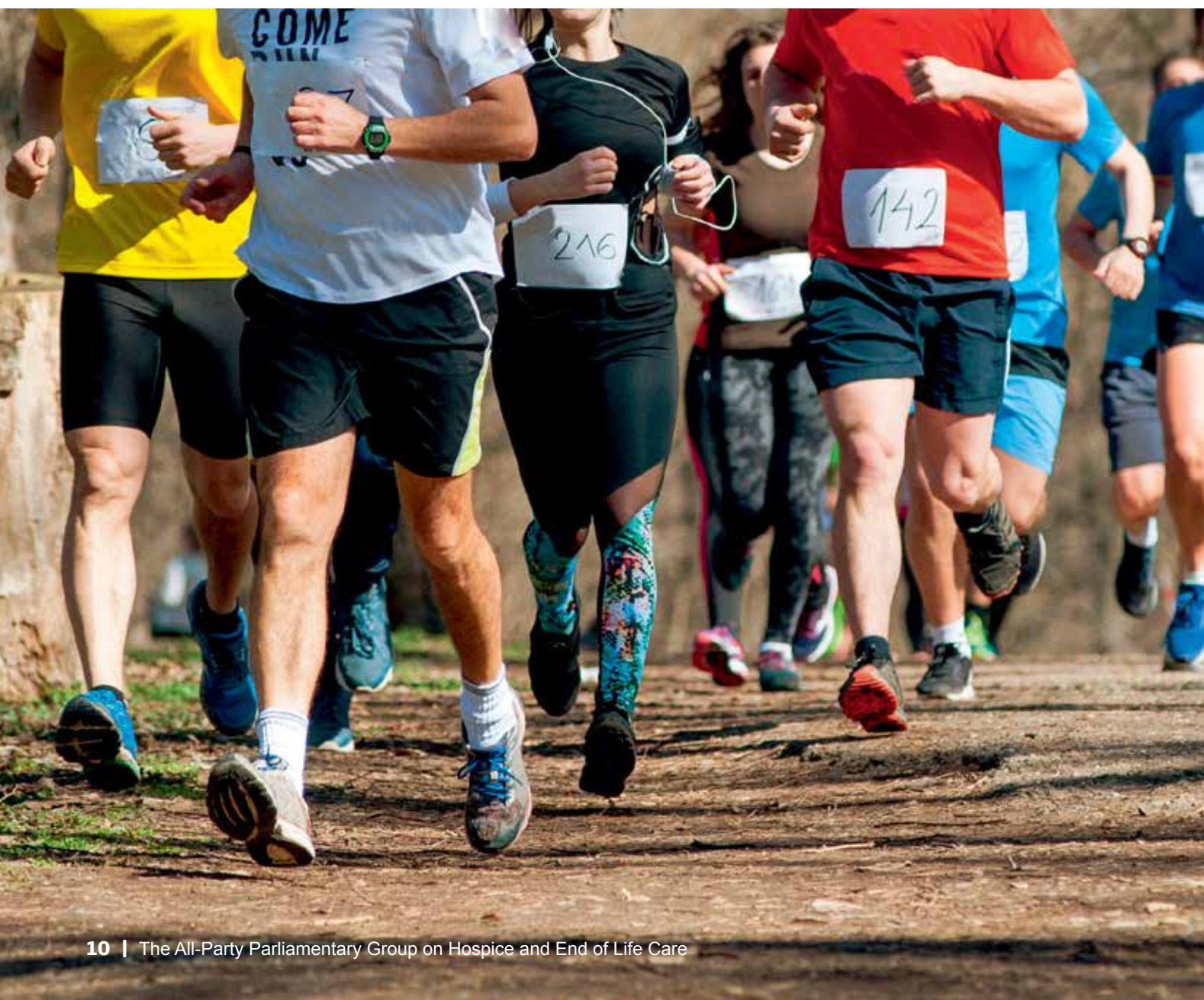
“The reliance on charitable funding to sustainably deliver services that form core components of clinical pathways reflects poorly on how this area of care is valued and prioritised.”

St Rocco’s Hospice.³⁴

There is value to having a charitable element to hospice services, as it fosters a deeper connection with the community and allows flexibility in the enhanced services they can offer. It also enables hospices to fundraise for services that have great value to their community but are not within the remit of Government or NHS funding.

However, evidence to this APPG demonstrates the risks and harms of what has become an overreliance on these funding streams. Government should readjust the balance between statutory and charitable hospice funding and ensure local commissioning is fulfilling the intentions of the statutory requirement. The starting point for this should be developing a national plan to ensure the right funding flows to hospices, which includes many of the measures set out in this report’s recommendations.

Many hospices feel that their reliance on charitable fundraising is symbolic of the lack of value the NHS and Government places on palliative and end of life care. One hospice argued that the current funding system ‘undermines the specialism of the clinical staff’ as staff in the same roles in other settings would be fully NHS funded.³⁵



2. Impact of the new ICS system and statutory requirement

2.1: Changing system, changing relationships

The 2022 Health and Care Act put into place a shift from CCGs to ICSs. While in the previous system, there were over 200 CCGs when established, there are now 42 ICSs, meaning most ICBs cover a larger footprint than the previous CCGs.³⁶

In their evidence, some hospices speak fondly of the ‘healthy and positive’ relationships and mutual understanding they built with their previous commissioners at CCGs. When ICBs were introduced, these established relationships disappeared and hospices moved into the scope of one, or several, new systems, with new commissioning teams managing complicated new responsibilities. This requires significant investment of time and resources by hospices to rebuild relationships with ICB commissioners, as they have the majority of responsibility for hospice funding in England. This is particularly difficult for children’s hospices, which typically provide services to greater geographical areas and therefore have more relationships to maintain. One hospice explained that while they have generally good relations with their ICB, the ICB has had to cut staffing costs and is experiencing increased turnover, forcing the hospice to continuously build new relationships.

Some hospices have been able to build or maintain excellent relationships with their local ICBs. One hospice told us that their ICB are ‘amazing’ to work with and provide great support. Unfortunately for many, there has been a marked decline in the quality of these relationships despite the efforts of hospice teams. One hospice, which spoke of previous success when discussing inflationary uplifts, had experienced a reduction in funding since the Health and Care Act came into effect as ‘dialogue was avoided and negotiations protracted’.

It is clear that this heavy reliance of government funding for essential services on local relationships carries risks. There needs to be an agreed national

minimum standard for the level of provision of palliative and end of life care the ICBs must ensure is provided for and funded. There must also be national quality standards, which commissioners can use to assess the quality of the services they are commissioning and ensure they are getting value for money.

Additionally, NHSE should provide guidance to ICBs on how to commission VCSEs, including a timeline for commissioning decisions to ensure negotiations are timely, transparent and proportionate.

2.2: Profile of hospices and end of life care

The profile of palliative and end of life care and the services delivered by hospices have also been impacted by the new systems. Several respondents to our call for evidence argued that the statutory requirement improved the prominence and prioritisation of palliative and end of life care in discussions and in the minds of ICB members.

Research by Hospice UK in late 2023 found that 23 of 42 ICBs prioritised adult palliative and end of life care in their Integrated Care Strategy (which is held by the Integrated Care Partnership) and/or Joint Forward Plan (JFP) (held at ICB level).³⁷ In previous research, the National Bereavement Alliance found that only 9 of the 36 Integrated Care Strategies published at the time mentioned bereavement, although this may be addressed within other plans.³⁸

The APPG heard from representatives of ICBs across England about their priorities for end of life care within their JFP. For one ICB, this included access to co-ordinated 24/7 care, and fair access driven by early identification and reduction in inequalities.³⁹

However, there was no correlation between those who highlighted palliative and end of life

care in their plans, and those who provide better funding for hospice care.⁴⁰ This is evidenced in hospice submissions to this inquiry, which highlight that, even where there have been positive conversations about end of life care at ICB level, this has not resulted in material improvements in commissioning. Recent Freedom of Information requests by Together for Short Lives also found that, despite the legal duty, only 31% of ICBs were able to say how many children and young people with life-limiting or life-threatening conditions who live in the areas they serve accessed hospice care in 2022/23. 14% were unable to say how much money they spent on children's hospice care at all in 2022/23.⁴¹

“Senior hospice clinical leaders do actively participate in the overall [End of Life] planning infrastructure which has been established under the ICS structure. However, this engagement has yet to yield any material improvements to service provision.”

Anonymised hospice.

To begin to address this need for consideration of palliative and end of life care to follow through to material change for these services, ICBs must ensure the prominence of palliative and end of life care in the Integrated Care Partnership's joint strategic needs assessment and that this needs assessment informs their own commissioning decisions.

Further many hospices are finding it difficult to get their voices heard. ICBs are responsible for a larger geographical footprint and number of providers than CCGs previously were. Hospices have found that under this new system, they are a smaller player than previously and are not given a platform to share their perspectives.

“It has been a struggle to ensure services for Palliative and End of Life Care for both Adults and Children are included in Forward Plans and Strategic Plans as PEOLC is frequently overlooked.”

Anonymised hospice collaborative.

In some areas, hospices have sought to address this by forming collaboratives, which provide a single clear voice for local hospices, share learning and seek opportunities to build partnerships with the ICB.⁴² A national palliative care provider shared that many of its hospices across the UK have joined collaboratives, and that several of these have been successful in amplifying the concerns of hospices and addressing short term pressures. One collaborative secured a £1.8m grant between its 10 members in March 2023, to help with sustainability.

However, despite some evidence of success, many hospice collaboratives have been unable to secure improvements to their funding and long-term sustainability. Another hospice shared that through working with local hospices, they have produced collaborative plans on key issues such as virtual wards and 24/7 access to advice, but have so far not secured funding. Further, while being represented as a collaborative is efficient, this still equates to less influence than many hospices were used to in the previous system, when they would each be able to represent their hospice in its own right.⁴³

“Hospice Collaboratives have been successful in some instances in using their collective voice to address short term pressures but are not yet able to fully replicate previous strategic relationships.”

National palliative care provider.

Others have found that the variation in situation between hospices is a barrier to collaboration. Even neighbouring hospices may have very different funding from the local ICB, different levels of donations and different costs. This inequality in experience, with some hospices in a sustainable position and others reducing services, makes it difficult for hospices to work together on an equal basis. Therefore, for hospice collaboratives to be more widespread and facilitate better communication between commissioners and end of life care providers, ICBs need to take a more consistent approach to commissioning. The UK Government must start work to develop reference costs and quality standards that can be used by

commissioners to better understand what they should be paying for different hospice services.

2.3: Understanding of hospices and end of life care

Another impact hospices have experienced following the introduction of Integrated Care Systems is the loss of end of life care knowledge and understanding at this level. As mentioned, hospices lost commissioners they spent years building relationships with, and many of the teams who replaced them are unfamiliar with end of life care and having to understand multiple new commissioning areas at once.

Hospices are finding that these new commissioning teams do not have detailed understanding of the services hospices can and do offer, or the care people will need at the end of their life. A children's hospice feel that commissioners lack understanding of the role of the short breaks service they provide, and that planned short breaks form 'the essential foundations of the child's journey to end of life'. In its evidence, an adult hospice identifies a lack of understanding of the role hospices play, in managing symptoms and preventing emergency hospital admissions or ambulance call outs.⁴⁴ Another hospice argued the need for hands-on care for people at the end of their life is not understood or reflected in funding for end of life care services.

This lack of understanding concerns hospices, as it means that the funding provided, and the services this funding is earmarked for, does not always match up with the demand for services and the ways they are used. Furthermore, this lack of insight into hospice services can make it easier for commissioners to stop or suddenly change funding as they did not have a good enough understanding of the consequences of such a decision on the local population.

Along with the lack of understanding of service delivery, hospices have also noticed a lack of understanding of the costs involved in hospice provision. This problem does not only arise at ICB

level but is also reflected in the guidance provided to ICBs by NHSE, which does not reflect the varied reality of hospice funding.⁴⁵ This is compounded by a lack of understanding of the variation in hospice costs and commissioning needs due to the different kinds of hospices, for example, hospices without an inpatient ward or physical building have very different overhead costs to hospices with large buildings.⁴⁶

The Speciality Advisory Committee for Palliative Medicine Higher Specialty Training submitted evidence to this inquiry highlighting its concern over a lack of understanding at ICB level of the training and workforce needs in hospices, and the funding needed to address them.⁴⁷

“While hospices are working to broaden the range of multidisciplinary workforce and therefore build resilience, this is not being acknowledged or matched with funding from their NHS partners or investment by ICBs.”

The Speciality Advisory Committee for Palliative Medicine Higher Specialty Training.⁴⁸

Due to this lack of understanding of hospices, palliative and end of life care need and the role of end of life care commissioning, hospices express that they are having to take the lead in relationships and negotiations with ICBs. One shares that they brought the statutory guidance produced by NHSE to the attention of their ICB, as they had not been aware of it. This demonstrates the need for more support from the centre to ensure ICBs understand and are properly implementing the NHSE guidance and their requirements.

NHSE must undertake a proactive programme of support to ICBs on how to interpret the NHSE guidance on commissioning palliative and end of life care and what they are required to commission in their area. It must also hold ICBs accountable by ensuring Joint Forward Plans deliver the priorities of Integrated Care Strategies based on local need assessments.

2.4: Lack of clarity on ICB decision making

The new ICS system has also led to a lack of clarity regarding where decisions are made, or contacts are held. ICBs often do not properly communicate who has decision making authority for hospice funding or holds responsibility for end of life care. This lack of clarity on where decisions are made means hospices do not know how to build relationships that support the commissioning of their services. Some hospices are particularly unclear on what role, if any, place level has in commissioning and how funding can flow from discussions at this level.

“The lack of identifiable individuals with clear commissioning and decision-making powers has left commissioning in a challenging state of paralysis.”

Anonymised hospice collaborative.

This lack of clarity has slowed contract negotiations for some hospices. There is not only a lack of contact with decision makers, but also a lack of transparency and clarity on how decisions

are made and the processes. This appears to have impacted trust between hospices and commissioners, particularly when there is not a clear visible process behind changes to funding.

These challenges are likely related to the ‘immaturity’ of these new systems, and the amount they are grappling with. Many of these barriers may be addressed as the system grows to understand how they work in practice and what support their providers need. In the meantime, ICBs can help by ensuring hospices have a named senior contact within the ICB who has responsibility for commissioning in their area.

The Children’s Hospice Grant, which previously has been allocated centrally by NHSE, could be delivered via ICBs in 2024-5. There are concerns about whether ICBs can manage this at this point in time and whether the money will flow through from central Government to ICBs and then to children’s hospices as needed.⁴⁹ It is clear that, at least for the next few years, the Children’s Hospice Grant funding must be ringfenced to ensure that it reaches intended services.



3. Shortcomings of the hospice funding model

3.1: Funding for hospices and ICBs

The overwhelming majority of those who submitted evidence to this inquiry made clear that funding for hospices, and for palliative and end of life care as a whole, is not meeting the need for care. The core clinical costs of hospice services are not covered by NHS funding, and so are precariously propped up by charitable donations.⁵⁰ This disparity is also worsening in the cost of living crisis, with the cost of providing their services increases while donations are under strain and NHS funding falls in real terms.

Hospices reflected that ICB expectations of hospice services and their contribution to palliative and end of life care were not in line with commissioning decisions, with some hospices feeling they are plugging gaps in the NHS end of life care service provision, and yet local contracts are not covering the costs of core clinical services.⁵¹

“The role of our hospices is crucial to how we operate and for ensuring there is the ongoing and effective support of patients, residents and their families who are dealing with end of life and life limiting conditions, and for supporting end of life in the most appropriate place, ideally home. The role and contribution of Hospices in all their forms is crucial to meeting the needs of those at the end of life or with life limiting conditions.”

Mid Yorkshire Teaching NHS Trust.⁵²

This lack of funding is resulting in a reduction in service provision and hospices having serious conversations about reducing their offer. For example, one shared they were unable to use 4 out of their 20 beds due to the lack of funding.⁵³

Historically, funding for hospices has been consistently low, made available from different sources with different requirements and run on a short-term basis. The majority of hospices have received government funding through rolling grants that require yearly renegotiation.⁵⁴ Sue Ryder argues that the government funding hospices receive was ‘patchy, insufficient and short term, and made of non-recurrent funding pots’.⁵⁵

This makes it difficult for hospices to plan for the future, expand their services, or even offer permanent employment contracts to staff.⁵⁵ It also means hospices must use significant resources to ‘refresh and update financial forecasts’ and bid for small pots of money.⁵⁷

“I have yet to meet a hospice colleague who can explain the funding formula by which their org receives funding, but all tell of time-consuming bids to access pots of money.”

Individual with lived experience working in the hospice sector.⁵⁸

Despite the new requirement for Integrated Care Boards to commission palliative care to meet their population’s needs and additional statutory guidance, commissioning has not improved. Many previous grants and models established by CCGs have simply been rolled over. As a result, hospices are funded on historic block contracts based on previous calculations that do not relate to current activity, cost and need.⁵⁹

One hospice shared that they receive their government funding through the Model Agreement of the NHS, which is not a commissioning document but functions similar to a donation, and provides no room for negotiation or leverage for more money based on service needs.

Hospices describe their funding as ‘stubbornly insufficient’ and ‘flat’, while costs rise.⁶⁰ Where hospices had seen a change in their funding following the amendment, this had been for the worse, with some reporting a ‘deterioration’ in the funding they receive from commissioners.

Many stakeholders who submitted evidence to this inquiry suggested that the worsening of matters since the Health and Care Act is due in part to the requirement to commission palliative care being issued with no funding behind it.⁶¹ Newly established ICBs are facing severe financial pressures and are having to balance many underfunded areas of care.⁶² Many ICBs do want to meet their population’s end of life care needs and support hospices, as evidenced by actions such as system plans, but do not feel they have the funds to do so. A hospice collaborative shared with this APPG that a local ICB committed to putting in place a 5 year funding agreement with the local hospices but had to put this on hold due to pressures to cut costs.

Hospices with positive relationships with commissioners, who they describe as ‘forward thinking and collaborative’, are told their ICB’s colleagues’ hands are tied by a lack of resource. These financial pressures are then being passed on to hospices and other system partners. A national provider of hospice care told this APPG that many of their hospices have been told by ICBs that there is ‘no money’ and to expect further cuts to their funding. An ICB that submitted evidence to this inquiry highlighted that, while they are being told by hospices that they are having to consider reducing their services, they are simply unable to allocate any additional budget to them.

In times of stretched resources, well integrated hospice services delivering quality services can alleviate pressures on the wider system and help the NHS and social care meet their broader goals. To support commissioning that maximises the offer of local hospices, national government must work to develop reference costs for different models of palliative and end of life care that accurately reflect the value of these services. NHSE must also undertake a proactive programme of support to ICBs focused on the NHSE guidance on

commissioning palliative and end of life care. This support should cover how to assess the wider value of services to system priorities and pressures.

Children’s hospices are concerned that the 2024-5 Children’s Hospice Grant will be added to the existing ICB budgets, without clear safeguards and ring-fencing, and therefore will not make it in full to the charities that it is allocated to.⁶³ Other hospices for children and young people have shared concerns that ICBs may use the grant as their full commissioning budget for children’s palliative care, removing any existing local ICB funding, which would effectively result in a 50% drop in statutory income for some services.⁶⁴ It is essential that the 2023-4 children’s hospice grant funding is ringfenced and that Government commits to maintaining this grant for the next five years to prevent this becoming the case.

“Safeguards are needed to guarantee that, as a minimum, children’s hospices continue to receive their current levels of NHS funding, including their Children’s Hospice Grant allocations. Without these safeguards, we are concerned that distributing the grant to ICBs to allocate could have serious consequences for the sustainability of children’s hospices and undermine support for children and young people with life-limiting conditions.”

Together for Short Lives.⁶⁵

3.2: Unjustified variation

Levels of funding for hospices vary significantly across the country and even between neighbouring hospices. This has long been the case, in large part due the lack of a standardised approach to commissioning and contracting.⁶⁶ Previously, CCGs determined funding for local hospices on an ad hoc basis, and the introduction of Integrated Care Systems has not yet addressed this.⁶⁷ Evidence submitted to this inquiry demonstrates this variation, with hospices sharing how they receive less funding per capita than other hospices in their area.⁶⁸

There is also significant variation in the total amount that each ICB spends on palliative and end of life care in their patch. Hospice UK submitted to this inquiry findings from a series of Freedom of Information (FOI) requests to ICBs made in mid-2023. This research found significant variation in the adult hospice spending of each ICB, ranging from £10.33 per head to just 23p per head.⁶⁹ A similar exercise undertaken by Together for Short Lives found variation in the spending on children's hospice care per child with a life limiting condition varying from an average of £511 in Norfolk and Waveney ICB to £28 in South Yorkshire ICB.⁷⁰

Not only is there variation in the amount of funding, but also what types of services are funded. This inequity in funding creates a 'postcode lottery' in the palliative and end of life care services populations can access.⁷¹

For example, the Association of Chartered Physiotherapists in Oncology and Palliative Care shared with the APPG that the majority of hospices do not receive specific commissioning for physiotherapy.⁷² This leads to serious variation in who is able to access this important service. They have heard from members working in hospitals covered by more than one ICB that the specific area a patient lives in determines whether they can refer them to physiotherapist at all upon discharge. In one area, the NHS community physiotherapy service specifically excludes those with a palliative diagnosis, and the local hospice is not commissioned for physiotherapy. This means there is no commissioned physiotherapy for palliative and end of life care patients in this area. Similarly, one hospice shared they have had to delay discharges from their inpatient unit due to a lack of Occupational Therapy.⁷³

The Association for Palliative Medicine of Great Britain and Ireland demonstrated that the case is similar for out of hours care, which is also predominantly charitably funded. As a result, only 1 in 4 areas in the UK have access to designated palliative care phone lines.⁷⁴

In their response to this inquiry, NHSE state that 'variation is to be expected as variation between population need exists'.⁷⁵ The Health and Care Act states that ICBs must commission palliative care 'necessary to meet the reasonable requirements' of the ICBs population, and therefore it is reasonable to expect funding to vary along with the complex needs of each community.⁷⁶ However, Hospice UK compared adult hospice care spending with the proportion of people over the age of 65 in each ICS, and found the region receiving the lowest hospice funding per head of the population, Cornwall and Isles of Scilly, has the highest percentage of residents over 65. Similarly, Norfolk and Waveney ICB, which provided a high level of children's hospice funding, provided just 74p of adult hospice funding per head of the population, despite having the 4th highest percentage of residents over 65.⁷⁷

Many stakeholders responding to this inquiry felt that the statutory guidance produced alongside the statutory requirement does not address this variation as it is too vague and allows commissioners to interpret the guidance at their own discretion.⁷⁸ As the Association of Palliative Medicine highlighted in their evidence, there is not a detailed description of what adequate specialist palliative care is to guide commissioning decisions.⁷⁹

"The lack of mandate or prescriptiveness within the NHS England guidance for ICBs has meant that we have seen radically different approaches being taken by the three Integrated Care Boards that we are commissioned by, and ultimately no changes have been made to how [the hospice] is funded or contracted."

Anonymised hospice.

National government must set out a national minimum standard for the level of palliative and end of life care that should be provided within all systems. NHSE should also undertake a proactive programme of support to ICBs on how to interpret the NHSE guidance on palliative care commissioning and what ICBs are required to commission.

3.3: Depreciation in the value of contracts

Hospices have seen variation in approaches to commissioning most clearly demonstrated in the annual increases, or lack thereof, applied to their contracts. Hospices are increasingly expected to deliver more with less and having their contracts reduce in real terms. Across the board, annual uplifts have not kept up with inflation, resulting in a £47 million real terms funding cut to hospices over the last 2 years.⁸⁰

As they provide essential services that would otherwise need to be provided by the NHS, hospices should at least be eligible for the same annual increases (or uplifts) to their contracts as NHS services. However, in 2022-24, 28% of ICBs provided uplifts that were below the basic NHS uplift to contracts with hospices in their area and 5% gave no uplift at all.⁸¹ One hospice shared with the APPG that they went 7 years without any uplift to their contract. As a result of a low uplift offer for 2023-4, at the time of submitting evidence, one hospice was still in contract disputes with their ICB and did not have a signed contract.

In 2022-23, NHS England released £1.5 billion of additional funding to ICBs to provide support for inflation and allowed ICBs to decide how best to distribute this funding within their systems. It is hugely concerning that, despite this additional funding, there is such significant variation and hospice contracts not receiving the minimum of annual increases.⁸²

The significant variation in the percentage uplifts hospices are receiving to their contracts contributes to the inequality and postcode lottery in funding for palliative and end of life care across the country. Several hospices shared that they received minimal uplifts and noticeably less than their local colleagues. One hospice shared that its ICB said the hospice would receive no uplift to its contract this year. The hospice then highlighted to the ICB that, with its funding and finances already vulnerable, not having an uplift would force a reduction in services. In response, the hospice was offered a 2.45% uplift. While this is a welcome improvement, it is a concerning demonstration of the lack of standardisation or clear process for deciding uplifts.

Hospices are managing serious long-term and short-term pressures on their finances, and while many are currently able to continue to provide services by using any existing reserves, they are rapidly approaching a time when this will not be possible. If we are to avoid hospice closures and the loss of essential services in a few years, increasing pressure on NHS services, ICBs must ensure uplifts to hospice contracts are equitable with uplifts received by NHS-run services and other hospices in the area. National government must also pursue a plan to ensure the right funding flows to hospices, which includes commitments to develop nationally agreed reference costs for palliative and end of life care and quality standards that services need to meet to be contracted.



4. External pressures on funding

The flaws of the current hospice funding model have been made more acute by external pressures and the changing need for palliative and end of life care.

During the pandemic, the need for the hospice sector to support the health and care system with increased mortality and provide complex care to patients skyrocketed, while their ability to fundraise was decimated by lockdowns.⁸³ At this time, Government took quick action, purchasing extra capacity from the sector to help protect the NHS, with a total value of almost £400 million across the UK over the course of the pandemic. Analysis by Hospice UK showed that the first £155 million in additional funding to hospices delivered £323 million of value to the NHS in England.⁸⁴

“The additional funding provided from NHS England...during the pandemic was essential to sustain service delivery and organisational viability during a time when our retail and fundraising services were forced to close and be suspended. This provides an illustration of the effective mechanisms that can be deployed by Government...ensuring the charities can be sustained through challenging financial times and supported to deliver essential patient care.”

*The Kirkwood.*⁸⁵

Many hospices responding to the inquiry emphasised their gratitude to national Government for this funding. In a previous inquiry, this APPG highlighted ways hospices used this money to maximise their value to the system. However, this demonstrates the fragility of the funding model and the need for a long-term plan to ensure hospices and local communities can rely on the local commissioning system.⁸⁶

4.1: Cost of living crisis

Rising costs, from energy and food prices to staff costs required to meet NHS pay rises, mean hospices across the UK are collectively budgeting for a deficit of £100 million in 2023-4.⁸⁷ As discussed above, uplifts in hospice NHS contracts have not followed inflation, and so these costs are rising without a matched rise in funding, both long-term and in the short-term emergency circumstances.⁸⁸

The cost of living crisis has also had an impact on the community’s ability to donate to charities, such as hospices, and therefore, as hospices struggle, and receive no improved support from government, the charitable fundraising they rely on is dropping.⁸⁹

The most troubling rising cost facing the majority of hospice services in England is staffing costs. Whilst pay rises for NHS staff are welcome and richly deserved, hospices have to keep pace with these increases without additional funding from Government.

69% of hospice expenditure is spent on staff.⁹⁰ Hospices employ clinical staff in many of the same roles as within the NHS, however, hospices are not provided with the necessary government funding to meet these new pay levels and charitable fundraising alone cannot make up the difference. Hospices pay what they can to their staff to try and keep pace with what they would receive if they worked in the NHS, but many fall short of matching Agenda for Change.

As a result, many hospice staff are doing the same job as their NHS colleagues but are being paid less for it. Hospice leaders shared with us how this seems to devalue their amazing staff, and how not being able to pay staff what they deserve, particularly during a cost of living crisis, is impacting morale across the organisation.⁹¹ This inequality of pay also impacts recruitment and retention of clinical staff for hospices.⁹²

“Government funding for hospices has not kept pace with inflation recently nor has it kept pace with the NHS Agenda for Change wage increases agreed on a national level. Given staffing costs are the biggest component in our expenditure, the current government funding system makes it difficult to recruit and retain staff.”

St Barnabus Hospice.⁹³

Lack of funding and increased staffing costs are already having an impact on hospice services. One hospice describes how they are having to go without key roles on Multi-Disciplinary Teams as they cannot afford to replace them.⁹⁴ For another hospice, workforce costs mean they will be forced to reduce services by the start of the next financial year, despite knowing there is a clear need to expand to meet demand.⁹⁵

Between February and March 2023, Hospice UK conducted a survey of 101 UK hospices and found that 7 in 10 felt that cost of living pressures were highly likely to result in having to reduce the volume of certain services. 7 in 10 also agreed that these pressures are highly likely to result in reduced support being available to the wider system. Hospice UK informed the inquiry that collectively hospices are budgeting for a deficit of over £100 million for 2023.⁹⁶ In their individual evidence to this APPG, hospices detail significant deficits and emphasise that, while financial buffers will help them survive a deficit year, this will eat into their reserves and very soon they will be out of options.⁹⁷

“The deficit budget will inevitably impact our reserves which through due diligence over the years by our Trustees has given us a small buffer for tough times. The reserves will only last for so long and without a significant increase in income our financial situation will become fragile.”

Beaumont House Hospice Care.⁹⁸

There is a need for national government to address the issue of staffing costs by providing emergency funding and thoroughly consider the impacts on the hospice sector within the NHS pay review process each year.

4.2: Changes in population need

A long term challenge facing the end of life care sector and the health and care system more widely, is the aging population and changes to what is needed and expected from care. The impact of this will be more severe in some areas than others, for example St Wilfred’s Hospice’s local population is already skewed to the 65+ demographic and is increasing.⁹⁹ It is clear, however, that this will impact every hospice in the UK, and the demands and complexities of their care.

According to sector projections, the number of people in the UK needing palliative care will increase by at least 25% by 2048 and the care needed will become increasingly complex, as people live longer with life limiting conditions and experience multiple co-morbidities.¹⁰⁰ 57.1% of hospice bereavement service managers also said demand for their services was much higher following the pandemic.¹⁰¹ There is also an increasing need for children’s palliative and end of life care, as due to advances in care babies, children and young people with terminal and life limiting conditions are able to live longer than before. This is fantastic, but it is vital that children’s palliative care services are properly funded and able to plan for this continued increase in demand to provide the needed support.¹⁰²

“We should expect increasing numbers of people coming to the end of their lives over the next 10 years, forecast by the ONS projections, therefore we should be planning for this.”

ICB End of Life Clinical Lead for Nottinghamshire.¹⁰³

It is evident that this is something hospices are very aware of, and many are already struggling to meet demand.¹⁰⁴

“There is an increasing demand for specialist end of life care with people living longer and with more complex healthcare needs. Referrals for our inpatient unit (IPU) and community services increased by 4% during 2022-23 compared to the prior year, and these were also 23% higher compared to four years ago.”

St Christophers Hospice.¹⁰⁵

Some ICBs and NHS services are undertaking population needs assessments, for both now and in the future to better understand if there is enough capacity in the right places to meet growing complexity and demand.¹⁰⁶ One ICB very clearly identifies that ‘hospices are struggling to meet the current levels of demand with existing levels of funding and capacity’ and will continue to struggle in future, however, due to the intense financial pressures on the ICB itself, despite understanding this need they do not have the money to support hospices to grow or innovate.

Care will need to innovate and adapt in order to meet this change in demand, but national charities that provide palliative and end of life care services across the country have found hospices ability to innovate and integrate into the system, and to plan for the future, is compromised by their funding

model.¹⁰⁷ The current approach to commissioning hospice services restricts the work they can do in collaboration with system colleagues and prevents them from establishing or expanding services for changing need as they cannot be sure they have the funding to maintain them.

In its evidence to the inquiry, Marie Curie highlighted that, increasingly, the need for care is shifting to the community as more and more people wish to die in their own home. This needs to be reflected in funding for palliative and end of life care services.¹⁰⁸

As NHSE identify in its evidence to the APPG, the majority of end of life care is provided in NHS hospitals, however, we know that a large proportion of people do not want to die in hospital.¹⁰⁹ To support people to die where they would prefer and allow timely discharge for those not best served in hospital, sufficient community palliative and end of life care services must be sustainably commissioned. The Nuffield Trust found that 66% of hospice patients are seen in the community, hospice services will remain essential as demand in the community grows.¹¹⁰ As St Christopher’s Hospice illustrated, not everyone needs specialist care at the end of their life, many at home and in care homes are supported by community nursing teams and social care teams, and so this must also be considered when ICBs and central government are planning the funding allocation for the future of palliative and end of life care.¹¹¹

5. Alternatives to the current model

In all, it is clear that the hospice funding model is no longer fit for purpose and does not maximise the value these services can bring to the system. Many of those submitting evidence to this inquiry suggested changes to the funding model that would offer more sustainable support to the hospice sector to ensure their vital services can continue.

Many hospices would not want 100% of their funding to come from Government sources. Having a charitable arm means hospices can be flexible with the services they offer and raise money for additional, enhanced services. Alternatively, 100% NHS funding would force hospices to drop ‘added value’ services.¹¹² The charitable aspect to hospices also strengthens their connection with their local community, providing an opportunity for people to come together to support a good cause in their community.

However, core clinical services that would otherwise need to be provided by the NHS should not be subsidised by local communities. This is the intent behind the statutory requirement for ICBs to commission palliative and end of life care but is not being fulfilled on the ground.

Hospices have differing views on the percentage of their total income that should be provided by government sources.¹¹³ However, many agree that the full costs of core clinical services that would otherwise need to be provided by the NHS should be met by commissioners. For one hospice, this includes pharmacy, pathology, patient community equipment, all CHC funded activity, palliative consultant costs, clinical nurse specialist and advance care planning.¹¹⁴

NHSE have provided guidance on core and specialist services ICBs should commission in their area, however this is not consistently applied on the ground. National government must develop a national minimum standard for the level of provision of palliative and end of life care that

must be provided within all ICBs to make it clear what should and should not be commissioned by ICBs. NHSE must also provide more proactive support to ensure ICBs understand and are able to follow this guidance, as well as developing further guidance on how to commission services from VCSEs more broadly.

There have been calls for standardised and nationally recognised reference costs for end of life care, to facilitate a more equal and logical funding model. Providers have attempted to use comparable NHS reference costs as proxy indicators for the costs of their services, however this has not been supported by their ICB as they argued ‘there is no nationally mandated tariff or price that can reliably be used for presentation of any conclusive evidence with regards to value for money of provision’.

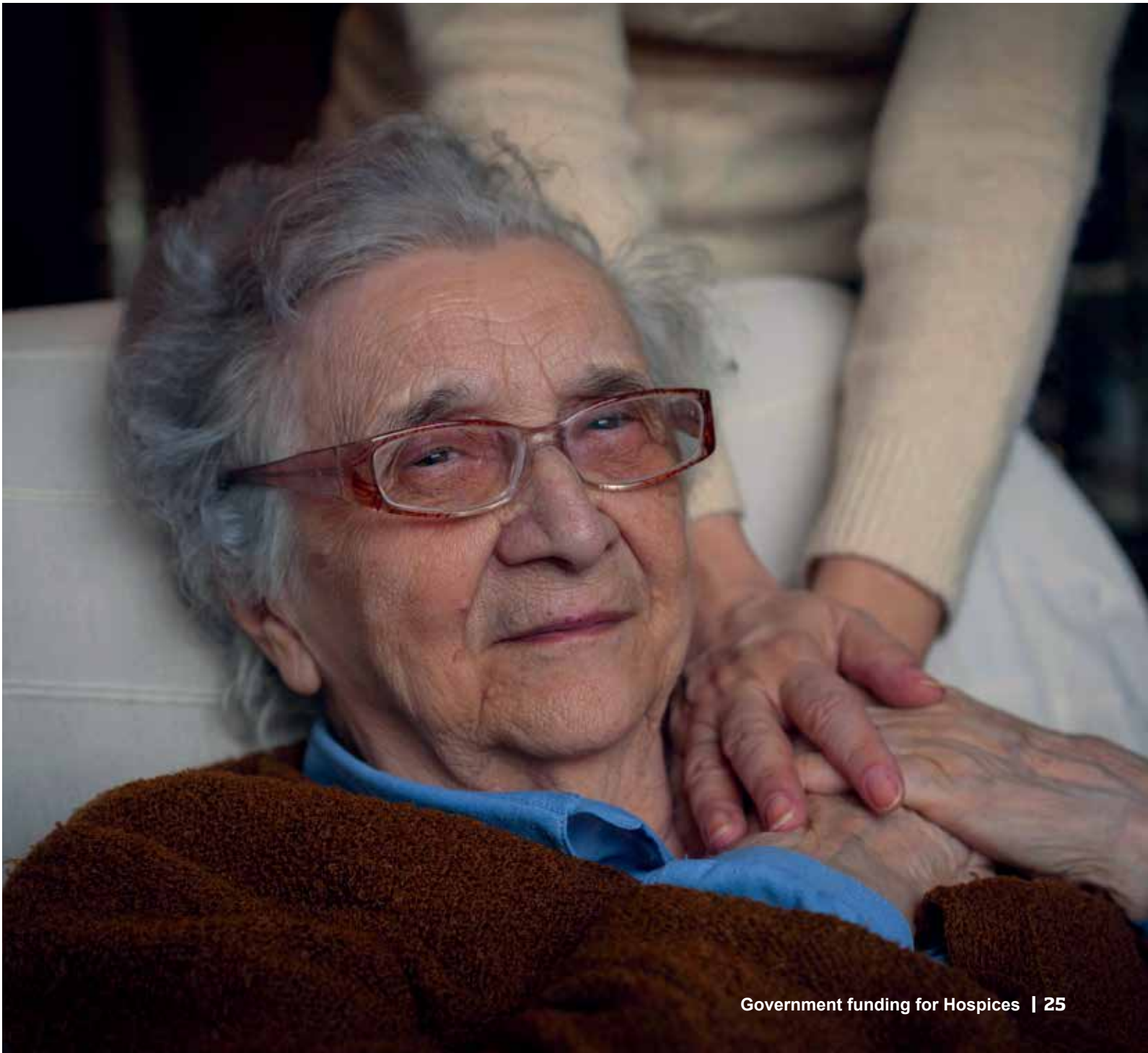
It is clear that a better understanding of the costs and benefits of different models of hospice care is needed. UK Government must conduct or commission a piece of work to understand the costs of providing different models of palliative and end of life care with the long-term aim of developing agreed reference costs that can be used by commissioners to provide a basis for the levels of funding they provide. UK Government must also develop national quality standards and outcome measures. All of this data will equip commissioners to benchmark hospice services and their value to the system.

“Hospices will rightly continue to fund raise and seek the support of local communities and this will continue to be critical to their success. However, ensuring there is reliable core central funding year on year would help provide more certainty about service delivery and development.”

Mid Yorkshire Teaching NHS Trust.¹¹⁵

When making changes to the hospice funding model, it is important that the postcode lottery of services is ended and any new model is consistent. That is why we are calling on the Government to set out a national minimum standard for the level of provision of palliative and end of life care that must be provided within all ICBs. ICBs must also work to provide consistent and fair funding to the services they commission, through ensuring uplifts to hospice contracts are equitable with NHS services and contracts are multi-year.

To adapt the hospice funding model to the needs of the population and the roles hospices play in the current system, action must be taken at the government, NHSE and ICB level. Key to making fair funding for hospices a reality is a plan from UK Government to adapt the funding model in order to realise the full potential of the hospice sector. This should include interim measures to support ICBs. However, its core function will be to set out a plan for how the funding model will change as a better understanding of the cost of delivery of different models of hospice care is developed and data is improved.



6. Reflections on the hospice funding model in Scotland, Wales and Northern Ireland

As health and social care is a devolved issue, this inquiry only makes specific recommendations with regard to hospice funding in England. However, it is important to understand hospice funding in Scotland, Wales and Northern Ireland, learn from these models and advocate for sustainable funding across the UK.

Hospices provide essential care across the UK. In Northern Ireland, sources indicated that the 4 charitable hospices provided care to 11,000 adults and 300 children in 2020/21.¹¹⁶ There are 14 independent hospice care charities in Scotland, providing support to 21,000 adults and children in 2022-23 and in Wales, 14 hospices provide essential care to more than 20,000 children and adults.¹¹⁷

Hospice funding models vary across the 4 nations, however hospices in each nation are funded by a combination of statutory funding and charitable donations.

In Scotland, the responsibility for commissioning palliative and end of life care sits with local integration authorities. On average just over a third of hospice' income in Scotland comes from statutory funding with hospices having to fundraise the remainder.¹¹⁸ The majority of statutory funding Welsh hospices receive comes via the seven Health Boards, with a small percentage funded centrally by Welsh Government. Wales developed a funding formula in 2008 in order to guide the delivery of ring-fenced government funding to ensure equality of evidence-based care provision.¹¹⁹ This defined the 'core' services government would fund hospices to deliver. This funding is delivered through Service Level Agreements and additional costs are met by the voluntary hospices.¹²⁰

In Northern Ireland, the funding system for hospices is in a particularly difficult position due to the Northern Ireland Assembly not being operational since early 2022. All hospices in

Northern Ireland receive statutory funding, however several are managing relationships with multiple commissioners, and all have complicated commissioning arrangements. National palliative and end of life care strategies are out of date and no new strategy is being developed due to a lack of funding.¹²¹

Despite the variations in their statutory funding models, many of the same challenges and concerns are shared by hospices across the UK. Health boards and local statutory partners in each of the devolved nations are under financial pressure and this has had an impact on hospice funding. Many Hospices Cymru members have received no uplifts from Health Boards this year and, as a result, many are considering making cuts to their services.¹²² The annual uplifts that hospices in Scotland receive varied widely, with an audit in April 2023 showing uplifts typically ranging from between 4% to no uplift at all.¹²³

"There is growing evidence and concern that rising staff and energy costs, workforce pressures, and increased demand and complexity of care pose an existential threat to the short and medium-term sustainability of children and adult hospice services in Wales."

*Hospices Cymru.*¹²⁴

In Wales, NHS pay increases over the last two years have raised total hospice staffing costs up by approximately £5.4 million. Welsh hospices are committed to paying a fair and competitive wage to their staff but, as with hospices in England, cannot keep pace with these pay rises. Hospices Cymru shared that all Welsh hospices are drawing on their reserves. This is not a long term solution, on average Welsh hospices have just 10 months in reserve, with some having only 3 months.

In July 2023, Hospices Cymru and Hospice UK found that every hospice in Wales is projecting a deficit for this financial year, representing a total deficit of £9.5m. Similarly, Scottish hospices are facing an expected deficit of £16 million for 2023 because of statutory funding not keeping pace with spiralling costs.¹²⁵

In Northern Ireland, the Strategic Planning and Partnership Group (SPPG) recognised the scale of cost pressures facing hospices and provided some additional funding, however this did not match the financial impact of cost pressures and there was little transparency on how allocations were made.

The variation in hospice funding seen in England is also a challenge in Wales, Scotland and Northern Ireland. Statutory funding for voluntary hospices varies significantly in Wales, particularly as Health Board funding for hospices is not ringfenced by Welsh Government. This results in some hospices receiving no funding, while others receive up to 50%. Hospice Alliance NI shared that almost every hospice contract in Northern Ireland is different, showing no consistency in approaches to commissioning. Hospice funding also varies between nations, with hospices in Wales receiving less overall government funding as a proportion of expenditure than those England, Scotland and Northern Ireland.¹²⁶

In Scotland, Scottish Government has made some progress towards a new national funding framework for hospice care, with a draft framework currently under development. However, the underlying issue of the £16 million deficit facing Scottish hospices has not been addressed. In addition, there needs to

be longer-term assurances that the hospice funding model will support future growth and demand, and that future NHS pay awards will consider and factor in the impact on the hospice sector.

It would be inappropriate for this APPG to make recommendations to address the funding challenges in Scotland, Wales and Northern Ireland. However, it is clear that something must be done to offer urgent support to these hospices and address their deficits. A long term funding framework for hospices in each nation should be developed that funds these services sustainably and recognises their role as equal partners in the system.

In Wales, the Minister for Health and Social Services has agreed that the final phase of their Palliative and End of Life Care funding review will consider the ongoing support that hospices need in more detail. Alongside this, Welsh hospices have requested financial support of £4m to meet the significant increases they are experiencing for their wage bills of core and relevant support staff delivering palliative care. Scottish government have also committed to producing a palliative care strategy and are working on its development. This is a welcome step, and this APPG would welcome reviews of hospice funding in each of the four nations.

Conclusion

This APPG received evidence from across the health and social care sector demonstrating significant variation and unsustainability in the commissioning of hospice services in England. This inquiry found that while the statutory requirement to commission palliative care was a welcome step and increased the profile of palliative and end of life care, this has not yet resulted in a more logical and consistent approach to funding of charitable hospices.

There have been drastic real terms cuts in the funding hospices receive from ICBs, as this has not kept pace with inflation. Additionally, the funding hospices receive varies significantly between services, without following a logical pattern of population need or service type.

Across the sector, there is a keen awareness that ICBs are not meeting the statutory requirement. To ensure hospices can provide their full benefit to the system, ICBs must commit to delivering their statutory requirement

and start by placing hospices on multi-year contracts, paying the full cost of commissioned clinical services and offering hospices the same annual increases as NHS services.

The evidence also demonstrates the need for national leadership from the UK Government. ICBs are new and have been handed a range of commissioning responsibilities with little detail on the services needed and severe financial pressures. It is vital that NHSE provides further support to ICBs to interpret their responsibilities, while the UK government produces a plan to adapt the hospice funding model over time.

The findings and recommendations in this report are intended to support national government and ICBs to reform commissioning of hospice services. Hospices are a vital part of the palliative and end of life care system in this country, and through suitable commissioning, they can be strengthened to fully realise the benefits of a sustainable and integrated hospice sector.



The APPG on Hospice and End of Life Care would like to thank all those who submitted evidence to this inquiry

Acorns Children’s Hospice	ICB End of Life Clinical Lead for Nottinghamshire	Royal College of Speech and Language Therapists
Alice House Hospice	Individual with lived experience	Royal Trinity Hospice
The Association of Chartered Physiotherapists in Oncology and Palliative Care	Individual with lived experience (NHS and Hospice Career)	Scottish Hospice Leadership Group
The Association for Palliative Medicine of Great Britain and Ireland	Individual with lived experience (Medical Director)	Severn Hospice
Beaumont House Hospice Care	Individual with lived experience (Patient and carer)	The Shakespeare Hospice
Blythe House Hospicecare and Helen’s Trust	Individual with lived experience (Frontline)	Shooting Star Children’s Hospice
Blythe House Hospicecare, Hospice Clinical Services Manager	Isabel Hospice	Shooting Star Children’s Hospice, Parents + Carers
Cheshire and Merseyside Hospice Provider Collaborative	Surrey Adult Hospice Chief Executives	South West London Hospices
Claire House Children’s Hospice	The Kirkwood	The Speciality Advisory Committee for Palliative Medicine Higher Specialty Training
Compton Care Hospice	Lancashire South Cumbria Hospices Together	St Barnabas Hospice
Cornwall Hospice Care	Leeds Palliative Care Network	St Catherine’s Hospice
Coventry and Warwickshire ICB	Lindsey Lodge Hospice	St Christopher’s Hospice
Demelza	Macmillan Cancer Support	St Gemma’s Hospice
Derby and Derbyshire ICB	Marie Curie	St Giles Hospice
Dignity in Dying	Martin House Children’s Hospice	St Helena Hospice
Dorothy House, Prospect and Salisbury hospices joint evidence	Mid Yorkshire teaching Hospitals NHS Trust	St Leonard’s Hospice
Eden Valley Hospice and Jigsaw Children’s Hospice	Mountbatten Hospice	St Michael’s Hospice
Florence Nightingale Hospice Charity	MSA Trust	St Raphael’s Hospice
Forget Me Not Childrens Hospice	National Bereavement Alliance and Childhood Bereavement Network	St Rocco’s Hospice
Greater Manchester Hospices Collaborative	NHSE	St Wilfrid’s Hospice (Chichester)
Hospice Alliance NI	North Devon Hospice	Sue Ryder
Hospices Cymru	North Devon ICB	Surrey Heartlands ICB
Hospiscare	North East and North Cumbria ICB	Together for Short Lives
Humber and North Yorkshire Hospice Collaboration	North London Hospice	Treetops Hospice
Ian Byrne MP on behalf of Zoe’s Place Baby Hospice	Nottinghamshire Hospice	University of Surrey
	Overgate Hospice	Wakefield Hospice
	Prince of Wales Hospice	West Yorkshire Hospices collaborative
	Queenscourt Hospice	West Yorkshire Integrated Care Board
	Rennie Grove	Wigan and Leigh Hospice
		Wirral Hospice

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