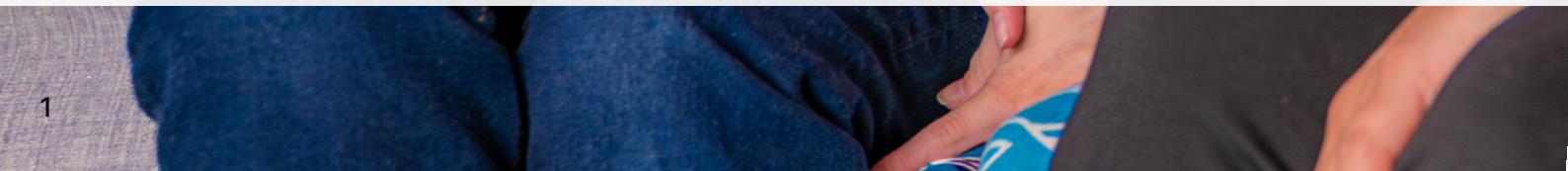
Home first, except when it matters most

together for short lives

How NHS commissioning is denying precious moments at home for families of children with serious illness – and undermines the shift from hospital to the community



Foreword

Every child deserves many moments of happiness together with the people they love. For many, children's palliative care is what makes those moments possible – providing children with serious illness the care they need, supporting families to be parents first, and enabling care that is wrapped around the whole family, at home, in hospital and in children's hospices. Across England, we know that it is possible to deliver this care to the very highest of standards. Every day, we see dedicated professionals going above and beyond to support children and families, alongside commissioners working to better align local services with national standards. Where this happens, families experience better quality of life as well as greater choice and control over the care they receive.

Yet, despite improvements over the past few years, access to this care remains inconsistent. As this report shows, too often the support a family receives depends on where they live rather than what they need. In some areas, gaps in planning, funding and accountability mean that essential elements of children's palliative care continue to rely on the goodwill of staff, rather than consistent and sustainable commissioning. This is denying families the opportunity to spend precious moments together at home – and undermining ministers' aim to shift care from hospital to the community. We must not accept this.

Frustratingly, this serious health inequality is not new. Over the past year, reports by the Commission on Palliative and End of Life Care, the Children's Commissioner and the House of Commons Health and Social Care Committee's Expert Panel have also shone a light on the postcode lottery facing families of children with serious illness.

That's why Together for Short Lives is here. We exist to make sure that every family can access high quality children's palliative care, when and where they need it. Step by step, hand in hand, day by day, so that every family is supported to navigate their child's life, death, bereavement and beyond. By working with our partners, supporters and the wider sector, we are determined to:

- Ensure equitable access to children's palliative care for all who need it.
- Improve the quality of care, ensuring the best support for families.
- Strengthen sustainability so families can rely on care when and where they need it.

Encouragingly, the profile of children's palliative care has never been higher, with policymakers from across the political spectrum increasingly recognising the difference this care makes. With growing consensus on the need for action, last year saw a significant government commitment: the development of a Modern Service Framework (MSF) for all-age palliative and end of life care.

For children and young people, the MSF is a vital opportunity to build on what already works, address long-standing variation and strengthen accountability so that high-quality care becomes the norm everywhere – not by chance but by design. By acting on the evidence and recommendations in this report, the government can ensure the MSF delivers lasting change and enables more children with serious illness, and their families, to receive the care and support they need.

Nick Carroll
Chief Executive,
Together for Short Lives

Executive Summary

• For thousands of families across England, children's palliative care helps them navigate their child's life, death, bereavement and beyond, and make the most of every precious moment they have together.

• Despite modest improvements in the past year, the patchy way in which children's palliative care across England is planned and funded means families can only access end of life care at home if they live in certain parts of the country, denying them precious moments at home and threatening the shift from hospital to community.

• The upcoming all-age Palliative and End of Life Care Modern Service Framework is a vital opportunity for ministers to fix the system for families of children with serious illness – but only if they work more closely with local NHS bodies to make sure key standards are met everywhere.

Key findings

• Across England, a range of different professionals and services work together to help families of children with serious illness achieve moments of happiness and joy by providing high quality children's palliative care.

• Many children and young people receiving palliative care have highly complex clinical needs. Their care often requires rapid access to specialist symptom management, coordinated multidisciplinary input, equipment provision, emergency care planning and psychologically informed support delivered across hospital, hospice, community and home settings.

• Its fundamental purpose is to ensure the best possible quality of life for every child with life-threatening conditions, life-shortening conditions or with severe medical complexity, while giving families real choice over where care is delivered, where their child dies, and what emotional and bereavement support they receive.

• Despite a clear legal duty on integrated care boards (ICBs) to commission palliative care that meets local need,[1] and extensive national policy guidance, commissioning remains highly inconsistent across England.

• While there have been improvements over the past year, this postcode lottery remains particularly stark in children and families' access to commissioned 24/7 end of life care at home, provided by nurses and supported by advice from specialist consultants in paediatric palliative medicine.

• In response to freedom of information (FOI) requests, less than a third of ICBs (31%) have provided evidence to Together for Short Lives showing that they formally commission this support.

• Over a third (36%) failed to provide evidence that they commission these services.

• National quality standards also require children's palliative care to be delivered by

multidisciplinary teams (MDTs) including members of specialist paediatric palliative care teams.

• Despite a modest improvement, nearly a third of ICBs (31%) are still unable to evidence MDT commissioning of any kind. Just 26% of ICBs explicitly evidenced commissioning this level of care.

• A consistent theme throughout the FOI responses we have received continues to be the lack of robust evidence underpinning what ICBs claim they are commissioning.

•Although all 42 ICBs responded,[i] 43% were unable to provide a service specification or similar demonstrating how their commissioning aligns with national standards.

• This not only limits the extent to which ICBs can hold local providers to account, but it also indicates that ICBs rely too heavily on informal or historic arrangements.

• Managed clinical networks (MCNs), recommended by NICE and widely recognised as central to improving children's palliative care,[2] play a vital role in connecting services, reducing fragmentation and supporting quality.

• Yet financial pressures have led several ICBs to recently withdraw funding, risking even more fragmented care, hindering the ability to achieve economies of scale at a regional level and removing effective systems for sharing intelligence, learning and working together.

• The result of these challenges is that many families do not have real choice about the care they and their child receive – and the UK Government's plan to shift care from hospitals to the community is under threat.

• We are pleased the UK Government has committed to developing a modern service framework (MSF) to set out a long-term trajectory for improving all-age palliative and end of life care in England, and we welcome the opportunity that we have had to shape it.

• We also welcome the interim update on the MSF which included a recognition of the specific needs of babies, children and young people. However, we are concerned that they are not explicitly referenced in the government's overarching palliative and end of life care goal.

• While just using the term 'person' could imply an all-age approach, history suggests that many local systems assume palliative and end of life care is just for older adults. Without a clear and explicit requirement to consider babies, children and young people from the outset, there is a real risk that their needs will be overlooked in commissioning decisions.

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[i] The 42 NHS integrated care boards (ICBs) which were created in July 2022 merged into 26 ICB clusters in April 2026; we issued our FOIs in 2025 to the 42 ICBs which existed at the time.

We therefore recommend the following action:

1. The government should ensure babies, children and young people are specifically mentioned in the wording of the government's overarching palliative and end of life care goal within the Modern Service Framework (MSF).

2. The government should examine whether children's palliative care would be more effectively commissioned at a national or regional level to create economies of scale and reduce variation.

3. The Department of Health and Social Care (DHSC) should consider a model in which specialist paediatric palliative care, as defined in the specialist tier of NHSE's children's palliative care service specification, is commissioned at a regional or national level to reduce variation and improve accountability.

4. DHSC should direct ICBs to work with neighbouring ICBs in their region to commission targeted and universal tiers of children's palliative care as set out in NHSE's service specification.

5. The government should establish clear accountability mechanisms to underpin the MSF and ensure its implementation, including actions that will be taken if ICBs do not meet the required expectations.

6. The government should provide ringfenced funding, that increases in line with inflation, to secure the future operation and sustainability of paediatric palliative care managed clinical networks.

Action to bring about a more sustainable funding model and workforce for children's palliative care is also vital. As we lead our sector to develop a whole-system vision for the future of UK children's palliative care, we will produce proposals to enable the government and the NHS to work with providers to make sure they have the resources they need to deliver the MSF and achieve a system which truly puts families at the centre.

Table of contents

Introduction

For thousands of families across England, children's palliative care helps them make the most of every previous moment they have together. By taking an active and total approach to care, and bringing together a range of professionals and services, children's palliative care is well-placed to help families navigate the complex system and deliver many moments of happiness.

Often spanning many years from diagnosis through to end of life, bereavement and beyond, the fundamental aim of children's palliative care is to promote the best possible quality of life and care for every child with life-threatening conditions, life-shortening conditions or with severe medical complexity and their family. Giving families real choice is key: a choice of place of care, a choice of place of death; and a choice of emotional and bereavement support.

For many young people, this support must also continue through transition into adult services, where fragmentation between children's and adult systems can create additional risks, disruption to relationships and inequitable access to specialist expertise.

Unfortunately for many, real choice is hard to come by. Over the past year, reports by the Commission on Palliative and End of Life Care, the Children's Commissioner and the House of Commons Health and Social Care Committee's Expert Panel have highlighted the inequities many families face in accessing high-quality palliative care.[3] While some areas benefit from high-quality services driven by clear and strategic commissioning, others lack the basic building blocks recommended by national guidance.

In England, national policy has long been clear about what good children's palliative care is. The National Institute for Health and Care Excellence (NICE) quality standard (QS160) describes the essential components of high-quality end of life care for infants, children and young people. Meanwhile, additional expectations have been set out in the NICE clinical guidelines (NG61), the Ambitions for Palliative and End of Life Care framework and the NHS England service specification for specialist palliative and end of life care services.

Taken together with the legal duty imposed on integrated care boards (ICBs) by the Health and Care Act 2022, these policy imperatives establish a benchmark for the care and support that should be commissioned across all local areas. Despite this, it is widely accepted that implementation of national guidance is inconsistent and varies across the country, often resulting in the voluntary sector stepping in to provide vital care and support. For example, gaps in the commissioning of children's social palliative care often means that holistic support such as practical, emotional and bereavement support is reliant on charitable income rather than sustainable commissioning arrangements.

In an effort to address the unwarranted variation, towards the end of 2025, the UK Government announced the development of a Modern Service Framework (MSF) to provide a long-term trajectory for improving all-age palliative and end of life care in England.[4] Due to be published in the autumn of 2026, the MSF provides an opportunity to re-emphasise the core elements of palliative and end of life care across all areas, clarify the minimum requirements of commissioning bodies and set expectations for how services should work together.

With the MSF on the horizon, this report offers timely evidence examining the extent to which ICBs are currently commissioning against national quality standards. It aims to show not just what is being formally commissioned, but how approaches to commissioning children's palliative care differ across the country and how this can drive unequal access to lifeline support for families.

To gather this evidence, in October 2025, we issued a series of freedom of information (FOI) requests to all 42 ICBs in England which existed at the time, asking whether ICBs commission services in line with the NICE quality standard (QS160) for end of life care for infants, children and young people.[ii] We asked ICBs the following questions:

1. Does your ICB have a children's palliative care service specification? (Yes/No). If yes, please attach a copy to your response to this request.

2. Has your ICB completed an Ambitions for Palliative and End of Life Care self-assessment? (Yes/No). If yes, please attach your completed self-assessment to your response to this request.

3. In your local area, does your ICB commission services which ensure infants, children and young people with a life-limiting or life-threatening condition and their parents or carers have opportunities to be involved in developing an advance care plan? (Yes/No/Partially). If yes or partially, please provide supporting evidence such as a relevant service specification.

4. In your local area, does your ICB commission services which ensure infants, children and young people with a life-limiting or life-threatening condition have a named medical specialist who leads and coordinates their care? (Yes/No/Partially). If yes or partially, please provide supporting evidence such as a relevant service specification.

5. In your local area, does your ICB commission services which ensure infants, children and young people with a life-limiting or life-threatening condition, their parents or carers and their siblings are given information about emotional and psychological support, including how to access it? (Yes/No/Partially). If yes or partially, please provide supporting evidence such as a relevant service specification.

6. In your local area, does your ICB commission services which ensure infants, children and young people with a life-limiting or life-threatening condition are cared for by a multidisciplinary team that includes members of the specialist paediatric palliative care team? (Yes/No/Partially). If yes or partially, please provide supporting evidence such as a relevant service specification.

7. In your local area, does your ICB commission services which ensure siblings and parents or carers of infants, children and young people approaching the end of life are offered support for grief and loss when their child is nearing the end of their life and after their death? (Yes/No/Partially). If yes or partially, please provide supporting evidence such as a relevant service specification.

[ii] FOI requests were issued before ICB clustering arrangements were finalised. All responses were therefore analysed on the basis of there being 42 integrated care boards.

8. In your local area, does your ICB commission services which ensure infants, children and young people approaching the end of life and being cared for at home have 24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care? (Yes/No/Partially). If yes or partially, please provide supporting evidence such as a relevant service specification.

9. In your local area, does your ICB commission services which ensure infants, children and young people with a life-limiting or life-threatening condition and their families have access to regular short breaks for respite? (Yes/No/Partially). If yes or partially, please provide supporting evidence such as a relevant service specification.

In total, all 42 ICBs responded to our request. Their responses were recorded and their supporting evidence was then analysed to determine if it met the relevant quality standard by using a simple yes/no/partially/unclear scoring system. This approach allowed us to identify the gaps in ICB commissioning and whether existing arrangements meet the expectations set out in the NICE quality standard.

Importantly, this report emphasises that commissioning is not the same as provision. An ICB may state it commissions a service, and this may be evidenced within a service specification, but this alone does not guarantee that families are able to access the care they need, at the scale or consistency required.

While this report highlights shortcomings in current commissioning, and the policy tests the MSF will need to meet to address these shortcomings, other significant challenges remain. Persistent workforce shortages and shortfalls in NHS funding for children's palliative care services are also key barriers preventing families from accessing the care and support they need, when and where they need it.[5]

Terms used in this report

For clarity, throughout this report we use the following terms:

• **Children with serious illness**: babies, children and young people aged 0-25 with life-threatening conditions, life-shortening conditions or with severe medical complexity.

• **Life-shortening conditions**: Conditions where death in childhood or early adulthood is likely due to the progressive nature of the condition or the absence of effective disease-modifying treatment.

• **Life-threatening conditions**: Conditions for which disease-modifying or life-prolonging treatment may be available but may fail, or where intensive therapies and interventions are required to sustain or prolong life. These conditions carry a significant risk of premature death even if treatment is pursued.

• **Severe medical complexity**: Children and young people with severe medical

complexity and vulnerability, including multi-system involvement, profound neurological impairment, technology dependence, or extreme frailty, where there is a significant risk of life-threatening events.

• **National quality standards:** Refers to the National Institute for Health and Care Excellence (NICE) quality standard for end of life care for infants, children, and young people (QS160).

• **National policy guidance:** Refers collectively to the NICE quality standard (QS160), the NICE clinical guidelines (NG61), the Ambitions for Palliative and End of Life Care framework and the NHS England service specification for specialist palliative and end of life care services.

• **Supporting evidence**: Any formal commissioning document that clearly sets out what services must deliver.

Dylan's story

"What palliative care did for our family was help us realise we had a choice."

– Sarah, Dylan's mum

When Sarah and Will's son Dylan was diagnosed with the rare neurodegenerative condition Sandhoff disease at 18 months old, their world changed overnight.

The first signs of Dylan's condition didn't appear until he was six months old. It started with difficulty weaning onto solids and subtle motor delays, later progressing on to seizures and the need for round-the-clock care, including a feeding tube and respiratory support.

Yet despite the challenges their family faced, Dylan was able to spend the majority of his short life at home, surrounded by those who loved and knew him best.

Their experience shows what is possible when children's palliative care is properly coordinated across hospitals, hospices, community services and home care. It also highlights a stark reality, that families in many parts of England are missing out on precious moments at home, because too often the support they receive depends on where they live and not what's needed or right for their family circumstances.

Shortly after Dylan's diagnosis, the pandemic hit, during which Sarah vividly recounts spending long periods in hospital with Dylan, isolated from the rest of the family.

"Being in hospital meant he couldn't go outside. We didn't have any of his equipment to help with standing and sitting, so he was restricted to his hospital bed with limited opportunities to move or change positions.

"It also meant as a family, we were all separated because it was during COVID. I was pregnant with our second child, and I don't think either of us felt that Dylan was getting the best quality of life. So, when the hospice rang and they said, 'do you want a way to get him out of hospital?' it was scary, yes, but at the time it felt like such a relief."

That moment transformed the family's understanding of what was possible. Rather than focusing solely on treatment, NHS professionals began working directly with Haven House's multi-skilled team to help the family take control of the situation and understand the choices they could make during the time they had left with Dylan.

"Until that point our approach was very much 'the doctors know best and they'll tell us what to do'. Whereas with palliative care and children with complex needs, it is much more complicated than that. The concept of palliative care is very different to a lot of other medicines. Knowing that there were choices we could make; that was a really important moment for us as a family."

Over the following two years, a network of services unfolded that ultimately made it possible for Dylan to be exclusively cared for at home. During that time, Sarah and Will welcomed his newborn brother, Benny, into the family, with Dylan able to play a major part in family life rather than spending long periods away in hospital.

"With the help of all those different teams working together, it meant that we were very much supported to care for him at home. We achieved that through being able to make very clear choices about not being admitted to hospital and what we felt would give him the very best quality of life. After that point, we never went into hospital again."

Great Ormond Street Hospital's specialist palliative care team provided access to palliative care specialists and a 24-hour advice line, with NHS community children's nurses responsible for monitoring Dylan's condition at home. Meanwhile, Haven House's hospice-at-home team supported the family with memory making, counselling and planning for end of life. NHS continuing care funded vital overnight nursing support.

Regular multidisciplinary meetings brought professionals together with Sarah and Will to review plans and ensure everyone understood the family's wishes.

When Dylan died in January 2023, just before his fourth birthday, he was at home with Sarah and Will by his side.

"Afterwards, hospice staff brought a cooling blanket and came to check on him regularly over several days. It meant we could hold him lots and say goodbye in our own time. It can be hard to understand if you've not been through it, but it really was beautiful. I just can't imagine us not being able to have done that."

Dylan's family were able to achieve their wishes because the right services were commissioned locally and delivered in partnership. But Sarah knows not all families have that opportunity:

"I'm very aware of how fortunate we were. After Dylan died, I joined the advisory council at Together for Short Lives because I wanted to make a difference for other families.

Dylan's experience shouldn't be exceptional. Everyone should be able to receive the same standard of care regardless of where they live. You're the one who knows your child best. That ability to choose means everything. It's heartbreaking to think some families don't get that chance."

Sarah and Will live in London and have recently welcomed a third child, Saunton, aged 1, alongside Benny, now aged 4.

Sarah, who is retraining as a music therapist inspired by her experience with Dylan, is making a powerful contribution to our advisory council, using her lived experience to shape both the work of Together for Short Lives and that of the wider children's palliative care sector.

A postcode lottery of commissioned care

In England, integrated care boards (ICBs) have a clear legal duty to commission palliative care that meets the needs of their local populations.[6] Despite this, findings from our freedom of information (FOI) requests have revealed that significant variation persists in the extent to which children's palliative care is being commissioned in line with national quality standards.

For many ICBs, service specifications play a central role in the commissioning process. By setting out the standards that providers are expected to deliver, they help shape what care is available. In 2023, NHS England (NHSE) published a service specification for palliative and end of life care for children and young people.[7] Built on established national standards, this model outlined a framework for delivering specialist level palliative care (SLPC) from identification of need through to end of life.

While some areas have aligned their service specifications with this national guidance to provide comprehensive support, others are falling short, increasing reliance on the goodwill of professionals and the voluntary sector to fill critical gaps. In many cases, this variation in commissioning is contributing directly to the inequitable access families experience when seeking the care and support they desperately need.

According to the NICE quality standards, babies, children and young people with life-threatening conditions, life-shortening conditions or with severe medical complexity and their families should be able to expect to be:[8]

- involved in developing an advance care plan
- allocated a named medical specialist to lead and coordinate care
- provided with emotional and psychological support, including information about how to access it
- cared for by a multidisciplinary team (MDT) that includes members of the specialist paediatric palliative care team
- offered support for grief and loss when the child is nearing the end of their life and after their death
- able to access 24/7 end of life care at home when the time comes, provided by nurses and supported by advice from a specialist consultant in paediatric palliative medicine.

The NICE quality standard also recognises the importance of children with serious illness and their families being able to access regular short breaks for respite. However, despite these nationally mandated expectations, our analysis has revealed that ICB commissioning does not consistently align with these standards.[iii]

[iii] Since responses to these FOI requests were gathered, Sussex ICB has confirmed plans to develop a 24/7 specialist paediatric palliative care service, which will most likely have implications for the future commissioning landscape in Sussex.

Involvement in advance care planning

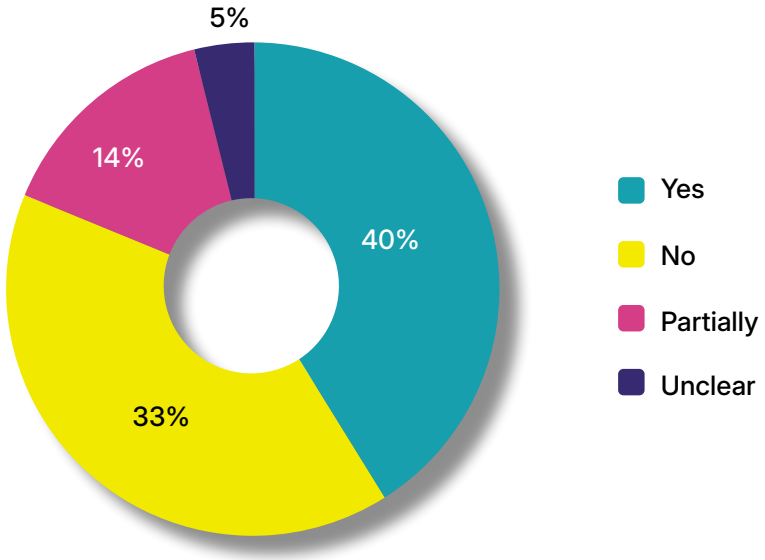
Advance care planning plays a crucial role in ensuring that care decisions reflect the needs, values and preferences of babies, children and young people with serious illness and their families. For commissioners, this means ensuring that services they commission actively support children, young people and their parents or carers to participate meaningfully in the development of advance care plans.[9]

Through our FOI requests, we have found that only two fifths of ICBs (41%, 17 ICBs) were able to provide a service specification or another form of supporting evidence explicitly requiring services to involve families in developing an advance care plan.

Meanwhile, a further six ICBs (14%) provided a specification that referenced some form of care planning but failed to cover co-production or inclusion of families' end of life care wishes, therefore only partially meeting the standard. For three ICBs (7%), their response indicated that a relevant service specification is currently in development and will in turn account for this standard.

At the other end of the spectrum, a third of ICBs (33%, 14 ICBs) were unable to provide any service specification or form of supporting evidence that demonstrated services meeting this standard were being commissioned.

The extent to which ICBs commission services to involve families in advance care planning in service specifications



Allocation of a named medical specialist to lead and coordinate care

Having a clearly identified lead clinician is essential for joined up, coordinated care, and ensuring the child or young person's needs are taken into account. In practice, a named medical specialist may include:[10]

- specialists in the child's underlying condition
- consultants and community paediatricians
- palliative care consultants
- hospice medical leads

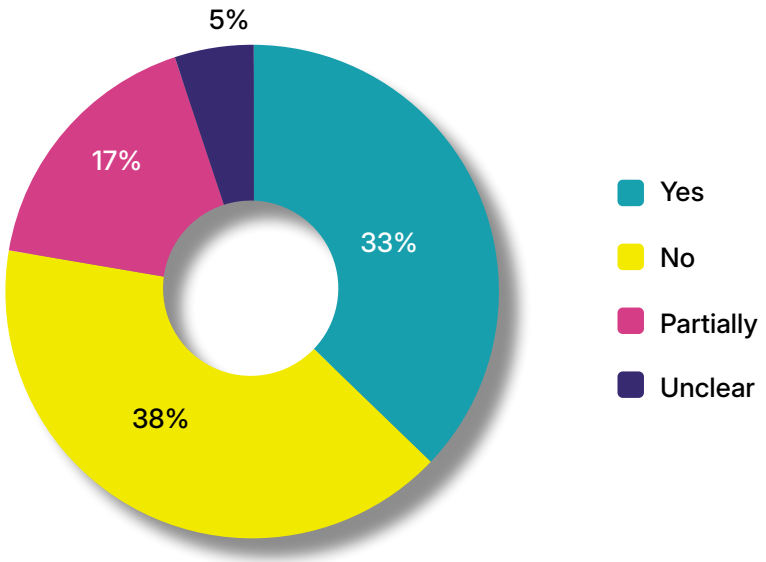
For commissioners, this standard requires them to ensure that services they commission provide every seriously ill child or young person with a designated medical specialist who leads and coordinates their care and acts as a consistent point of responsibility.[11]

Unfortunately, when assessing the extent to which ICBs are commissioning services in line with this standard, the picture is quite concerning. Only a third of ICBs (33%, 14 ICBs) were able to demonstrate the presence of specialist medical leadership within their commissioned services.

Meanwhile, a further seven ICBs (17%) referenced care being coordinated by a service or noted collaboration with medical specialists in their specifications, but did not evidence embedded specialist medical leadership, and therefore only partially met the standard.[iv] An additional three ICBs (7%) indicated that a relevant service specification is currently in development and is expected to address this standard once completed.

In contrast, over a third of ICBs (38%, 16 ICBs) failed to account for this quality standard at all in their service specifications or supporting evidence, highlighting a significant gap in ensuring consistent clinical leadership for children with serious illness and young people.

The extent to which ICBs commission services to ensure the allocation of a named medical specialist to lead and coordinate care in service specifications



[iv] ICBs were scored as partially meeting the quality standard when they reference care being coordinated by a service or named professional, but do not demonstrate the presence of specialist medical leadership in service specifications. ICBs were also scored as partially meeting the standard when only part of their geographical footprint is covered by specifications that meet the criteria. For this quality standard, a flexible approach was applied. ICBs were scored as 'Yes' where commissioned services clearly ensured medical specialist leadership, even if this was not explicitly described as a 'named medical specialist' for each child.

Provision of emotional and psychological support

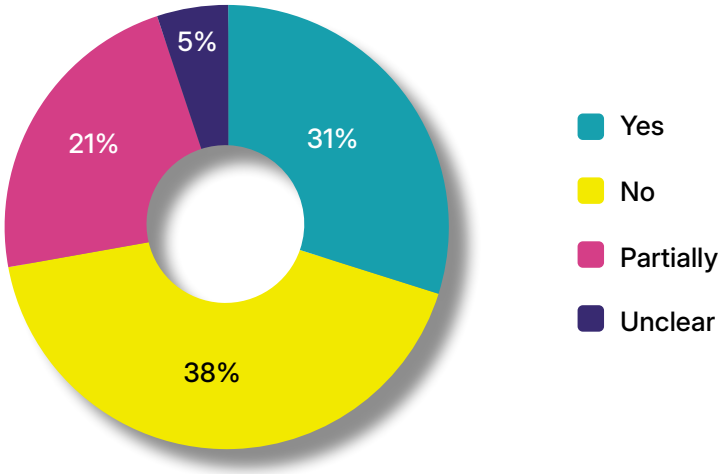
Emotional and psychological support is a vital component of children's palliative care, reducing distress and helping families cope with the significant emotional impact of a child's serious illness.

For commissioners, this national quality standard requires them to ensure that commissioned services include access to appropriate psychological support for children and young people with life-threatening conditions, life-shortening conditions and those with severe medical complexity. It also means considering how commissioned services can support siblings and ensuring that parents and carers receive clear information on how to access this support.[12]

Despite this, our FOI requests have revealed that less than a third of ICBs (31%, 13 ICBs) provided service specifications explicitly commissioning services to provide emotional and psychological support, and ensure families are provided with information about how to access it. Another 21% of ICBs (9 ICBs) only partially accounted for the quality standard in their supporting evidence.[v] A further two ICBs (5%) indicated that a relevant service specification is currently in development and will in turn account for this standard.

On the other hand, over a third of ICBs (38%, 16 ICBs) failed to account for this particular standard in their service specifications or supporting evidence, highlighting a significant gap in emotional and psychological support provision across England.

The extent to which ICBs commission emotional and psychological support, including provision of signposting/access information in service specifications



[v] ICBs were scored as partially meeting the national quality standard if they require emotional or psychological support to be provided in service specifications but fail to describe the access or signposting route.

Prescence of a multidisciplinary team including specialist paediatric palliative care professionals

Given the holistic nature of children's palliative care, a wide range of professionals often need to be involved in supporting a seriously ill child and their family to ensure their physical, emotional and practical needs are appropriately met. By adopting a multidisciplinary approach that incorporates input from members of the specialist paediatric palliative care team, steps can be taken to ensure necessary assessments are carried out and treatment is provided to resolve any distressing symptoms as quickly as possible.[13]

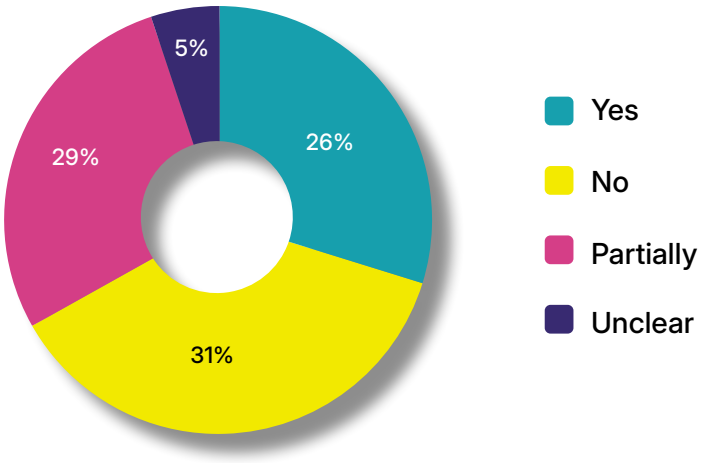
For commissioners, this means ensuring that commissioned services have clear and robust arrangements for MDT working, including guaranteed access to specialist input rather than reliance on ad hoc or informal arrangements. According to the NICE quality standard, the specialist paediatric palliative care team should include as a minimum:[14]

- a paediatric palliative care consultant
- a nurse with expertise in paediatric palliative care
- a pharmacist with expertise in specialist paediatric palliative care
- experts in child and family support who have experience in end of life care (for example, in providing social, practical, emotional, psychological and spiritual support).

Our FOI requests have revealed that around a third of ICBs (29%, 12 ICBs) required a multi-disciplinary approach in their service specifications or supporting evidence. However, only a quarter of ICBs (26%, 11 ICBs) explicitly specified that the MDT must include members of the specialist paediatric palliative care team.[vi] For four ICBs (10%), their response indicated that a relevant service specification is currently in development and will in turn account for this standard.

At the same time, 13 ICBs (31%) failed to provide a service specification or similar supporting evidence demonstrating that they commission MDT working with specialist paediatric palliative care involvement or, in many cases, that they commission MDT working at all.

The extent to which ICBs commission care to be provided by a multidisclipinary team that includes members of the specialist paediatric palliative care team in service specifications

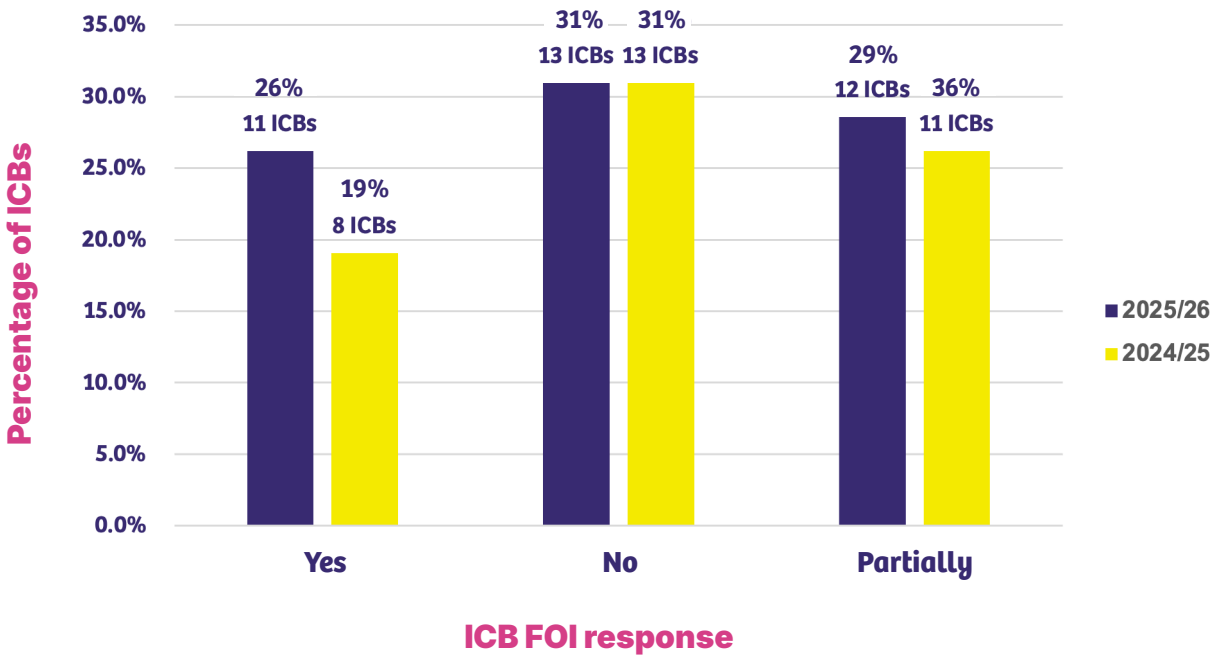


[vi] ICBs were scored as partially meeting this standard if they account for MDT working in service specifications but fail to mention the inclusion of members of the specialist paediatric palliative care team.

When compared to 2024/25, some modest improvements have been made. This year, the number of ICBs able to provide a service specification explicitly meeting this standard increased from eight ICBs to 11. While the number of ICBs unable to provide a service specification or similar meeting this standard remained at 13, the number with a specification partially meeting the standard increased to 12 ICBs, up from 11 in 2024/25.

Taken together, this indicates some progress but also highlights that a significant proportion of ICBs are still unable to evidence commissioning multidisciplinary care that includes specialist paediatric palliative care involvement.

The extent to which ICBs formally commission care to be provided by a multidisciplinary team including members of the specialist paediatric palliative care team: 2024/25 vs 2025/26



Support for grief and loss before and after a child's death

Pre- and post-bereavement support is central to helping parents, carers and siblings anticipate, navigate and cope with the profound emotional impacts of their child's death. In addition to supporting families with anxiety, depression and relationship challenges, this support can also help them communicate with other family members about what has happened and what they are experiencing.

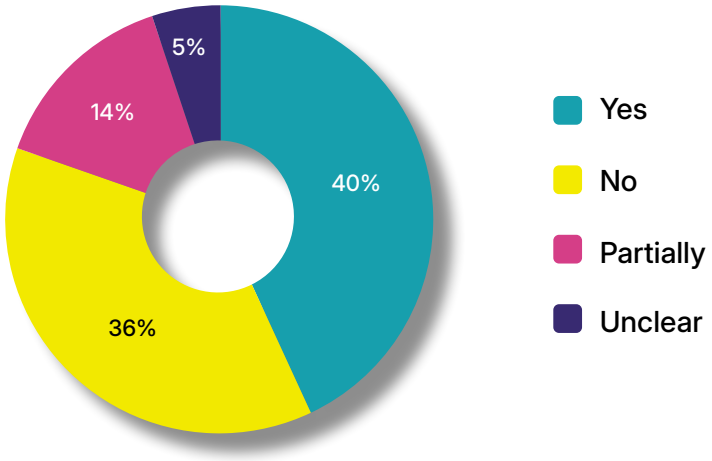
For commissioners, this standard requires them to ensure that that bereavement support for parents, carers and siblings is embedded within the services they commission, and that this support is available both as a child approaches the end of life and after their death.[15]

When assessing the extent to which ICBs are commissioning services in line with this standard, our FOI requests have shown that over two fifths of ICBs (41%, 17 ICBs) possess service specifications or similar supporting evidence that clearly meets it. Meanwhile six

ICBs (14%) have specifications that demonstrate bereavement support after a child's death but do not account for pre bereavement support, therefore only partially meeting the standard. Another two ICBs (5%) reported that their service specification currently in development will account for this standard.

In contrast, over a third of ICBs (36%, 15 ICBs) did not provide a service specification or similar clearly demonstrating that support for grief and loss was being commissioned.

The extent to which ICBs commission support for grief and loss when a child is nearing the end of their life and after their death in service specifications



Access to 24/7 end of life care at home

For many children with serious illness and their families, being cared for at home is their preference, including when a child is approaching the end of life. Round the clock clinical and specialist support at home is therefore critical in enabling families to choose the place of care that best meets their needs while ensuring timely management of distressing symptoms.

For commissioners, this standard requires them to commission services that provide 24 hour paediatric palliative care at home for children and young people approaching the end of life. This should include 24 hour access to children's nursing care alongside advice from a consultant in paediatric palliative medicine.[16]

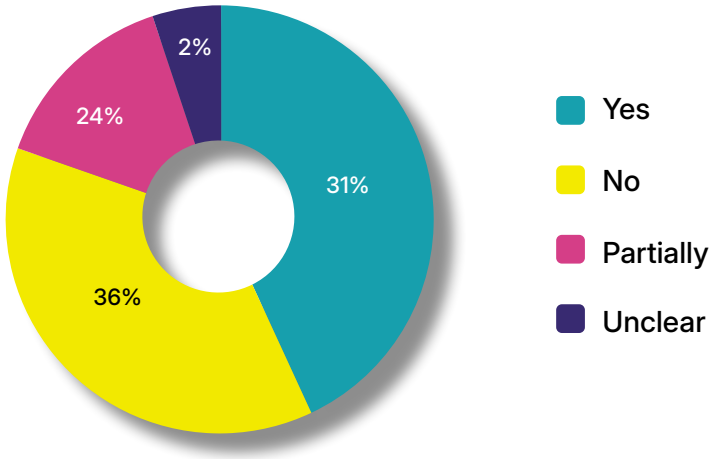
Delivering this safely and sustainably depends on sufficient community children's nursing capacity, including nurses with specialist palliative care competencies. In many areas, workforce shortages, limited out-of-hours provision and reliance on small teams create significant operational fragility and can limit families' real choice about place of care and place of death.

Access to specialist advice is especially critical due to complexity of many cases and to ensure distressing symptoms are managed as soon as possible. Research shows that specialist palliative care services improve quality of life and symptom control and can impact positively on place of care.[17]

Despite this, our FOI requests have revealed that just 13 ICBs (31%) possessed a service specification or similar evidence requiring services to provide 24/7 end of life care at home, delivered by nurses and supported by consultant-level paediatric palliative care advice. Meanwhile, less than a quarter of ICBs (24%, 10 ICBs) were able to provide a specification that partially met the standard. A further three ICBs (7%) indicated that the service specification they are currently developing will account for this standard.

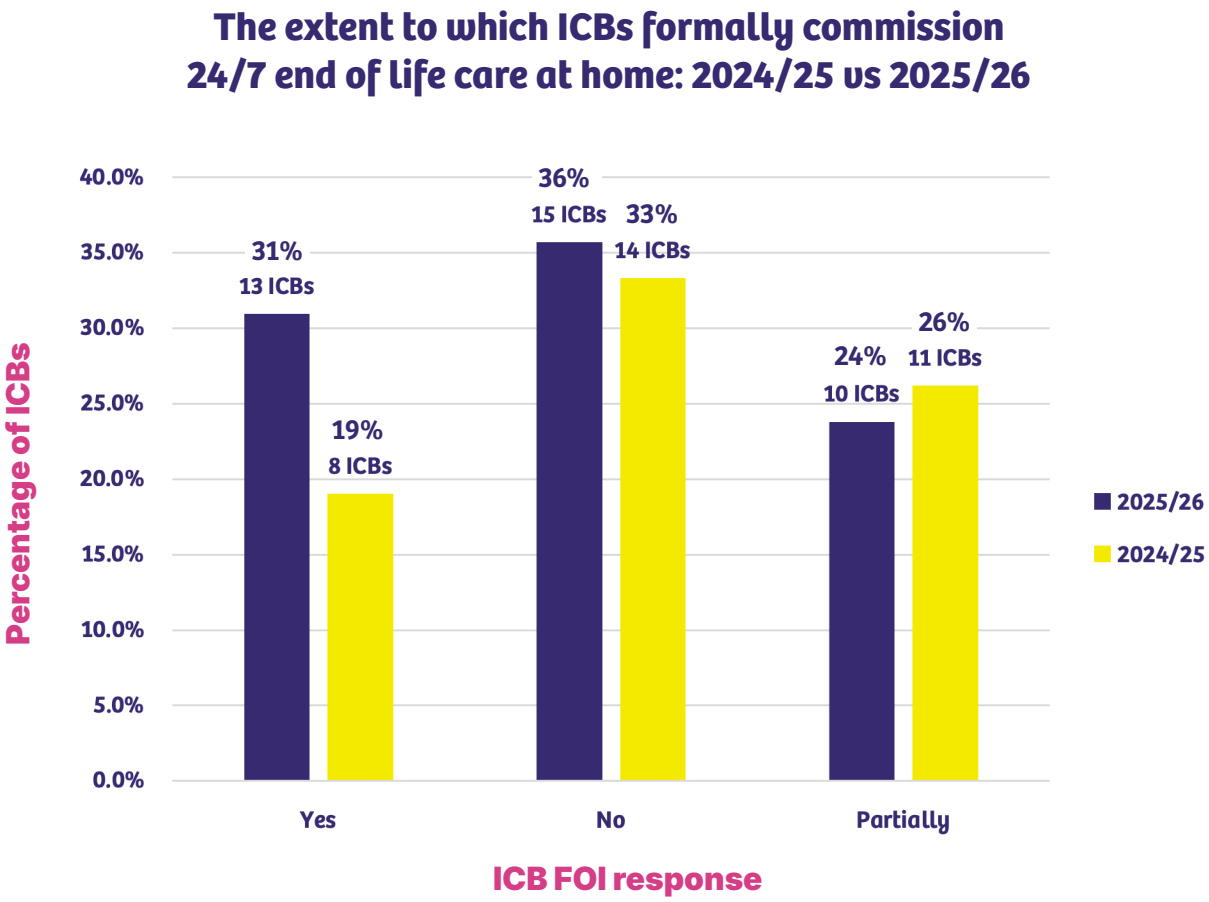
On the other hand, over a third of ICBs (36%, 15 ICBs) were unable to provide a service specification or any supporting evidence demonstrating that 24/7 end of life care at home was being commissioned, highlighting a significant gap in provision across England.

The extent to which ICBs commission 24/7 end of life care at home in service specifications



In practice, the absence of commissioned 24/7 community support can lead to avoidable emergency department attendances, prolonged hospital admissions, delayed discharges, ambulance call-outs and children dying in hospital, despite family preference for home care. It can also leave community clinicians without timely access to specialist advice when managing rapidly changing symptoms or clinical deterioration.

When compared to 2024/25, it is clear that some improvements have been made. This year, the number of ICBs able to provide a service specification or similar clearly meeting this standard increased to a total of 13, up from just eight the year before. At the same time, the number of ICBs unable to provide a specification meeting this national expectation increased slightly from 14 to 15. While progress is evident in a small number of areas, it is important to stress that over a third of ICBs are still unable to evidence commissioning this level of care, which could impact families' access to vital care and support.



Availability of sufficient respite care

While not one of the six quality statements explicitly mandated by NICE, research consistently shows that regular respite care is essential in helping parents and carers cope with the intensive demands of caring for a seriously ill child. Specifically, evidence has found that regular access to short breaks can help reduce emotional exhaustion and prevent mental health problems.[18]

Many parents and carers undertake highly skilled clinical tasks at home, including medication administration, enteral feeding, seizure management, airway care and monitoring overnight. Without reliable respite and community support, families are at increased risk of exhaustion, burnout and crisis presentations.

Respite care is therefore regarded as a fundamental component of children's palliative care. For commissioners, this means taking clear steps to ensure that babies, children and young people with life-threatening conditions, life-shortening conditions or with severe medical complexity and their families can access regular short breaks for respite as part of the services they commission.

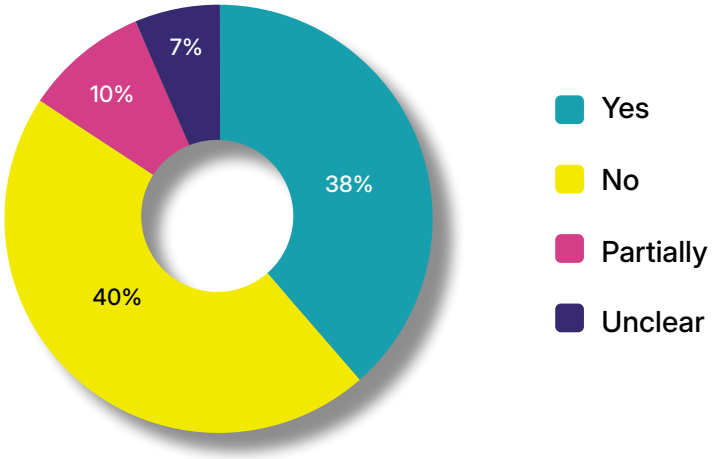
However, through our FOI requests, we have found that only 16 ICBs (38%) possessed a service specification that explicitly met this requirement.[vii] Meanwhile, 4 ICBs (10%)

[vii] ICBs were scored as partially meeting the standard when only part of their geographical footprint is covered by specifications that meet the criteria.

possessed a service specification that partially met the requirement.[vii] A further two ICBs (5%) indicated that the service specification they are currently developing will account for this standard.

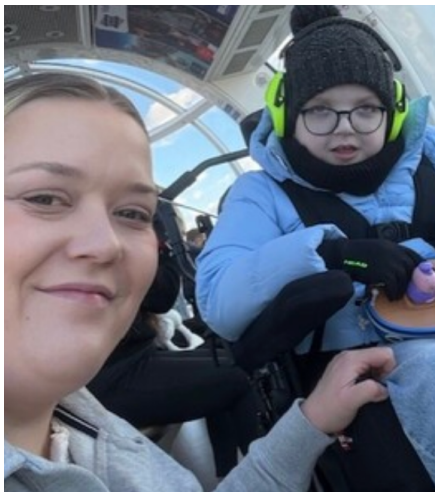
In contrast, over a third of ICBs (41%, 17 ICBs) did not possess a service specification or supporting evidence that met this requirement, highlighting significant inconsistency in respite provision across England.

The extent to which ICBs commission services to provide regular access to short breaks for respite in service specifications



Aidan's story

Aidan is eight years old and lives with cerebral palsy, epilepsy and severe gut dysmotility. This is his story, told by his mum, Zoe.



"At two and a half, Aidan's epilepsy took over. He lost his ability to eat, or swallow. He ended up in hospital every month for chest infections and most recently with a twisted bowel. He now needs to be fed intravenously and we've had digestive system complications ever since."

As Aidan's needs grew more complex, the family were referred to their local children's hospice for specialist palliative care. Zoe describes the profound impact of being introduced to other families and professionals who saw Aidan "beyond his medical complexities":

"Being referred to Helen & Douglas House was a game changer for our family, a massive game changer. The hospice introduced us to other families like ours and we started going to the parties. For the first time, Aidan was doing the normal things 8-year-olds do.

"The nurses there are amazing too. They see Aidan as a person, not just for his medical needs and are brilliant at knowing the ins and outs of the various systems we're currently navigating."

Aidan also has access to an NHS community nursing team and paediatrician, but their input is "limited" when it comes to any emotional or day-to-day support.

"The NHS community nurse teams are great but they're way overstretched and just aren't readily available for all the nitpicks you get caring for a complex child, or to support with some of our more traumatic experiences."

The family feel very fortunate to have been granted an NHS continuing care plan that provides funding for his carers five days a week. But that still leaves gaps in provision when the family has to cope alone.

"It doesn't factor in that I also have a severely autistic child – Aidan's brother – that likes to escape and run wild. So when my sole care is needed to help Aidan's carer, or my carer goes on holiday and their dad is at work, there's no cover and Kylan is just left to fend for himself."

It's made the world of difference, says Zoe, but the family have had to fight tooth and nail for it, resulting in Aidan having to spend long periods out of school until his needs could be met.

"The thing is, you're constantly dealing with people who aren't experienced in medically complex children or don't fully understand the medical side of things. As a result, parents like us are often left in a position where, unless you know exactly what to ask for, you don't get it.

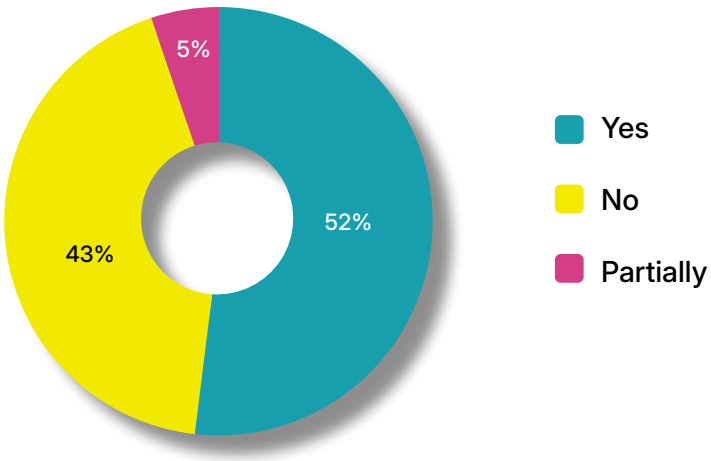
"There is an urgent need for someone to help join everything up and take on a coordinating role, someone who can see the bigger picture of what's going on for my family and help ensure children like Aidan get the support they deserve."

Evidence gaps undermine commissioning confidence

A consistent theme emerging from the FOI responses is the lack of robust evidence to substantiate many of the claims made by ICBs about the extent to which they are commissioning children's palliative care in line with national quality standards. Although all 42 ICBs responded to the FOI request and many asserted that they were commissioning services aligned with national expectations, a significant proportion were unable to provide a service specification or similar supporting evidence to verify their claims.

Overall, nearly half of all ICBs (43%, 18 ICBs) did not provide any service specification or evidence demonstrating that their commissioning activity matched the standards they reported meeting.[viii] Given the critical role that service specifications play in defining what providers are contracted to deliver, the absence of such specifications is concerning.

The extent to which ICBs were able to provide a service specification or similar

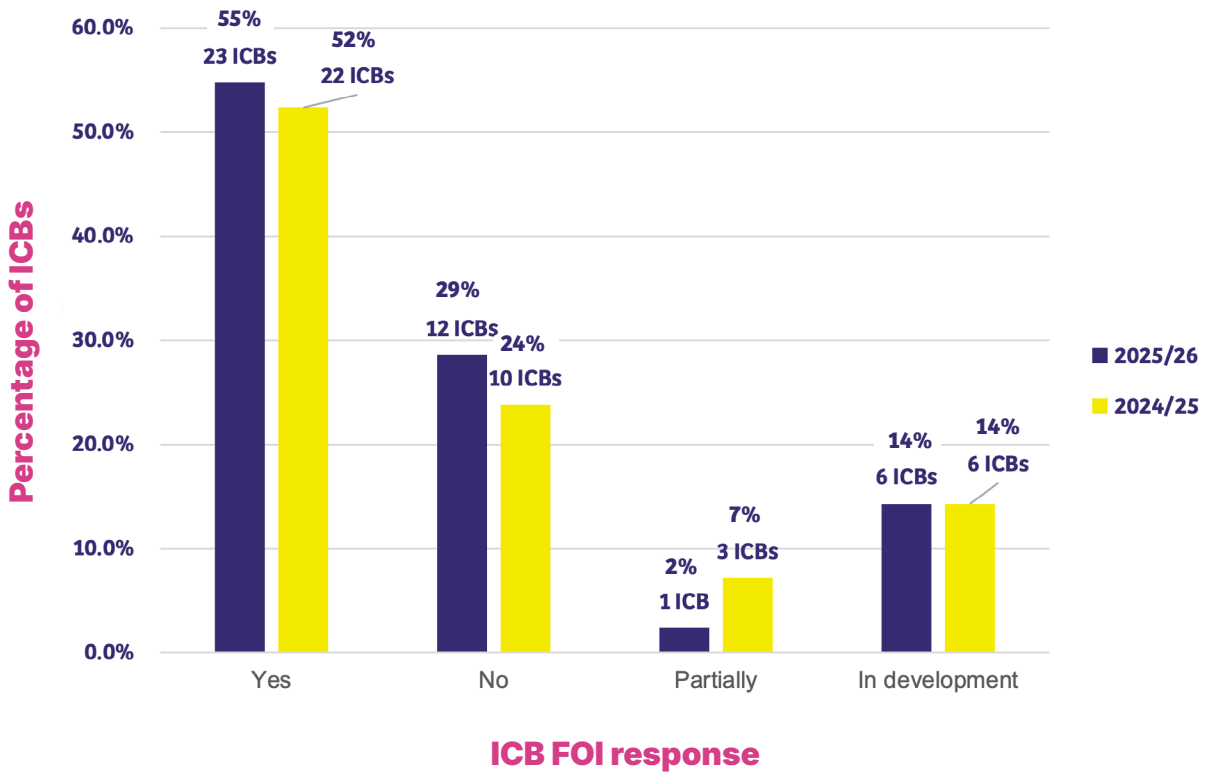


Compared with 2024/25, ICB responses indicate a small shift in the availability of relevant children's palliative care service specifications.[19] The number of ICBs reporting that they have a relevant service specification increased from 22 to 23. Over the same period, the number reporting that they do not have a relevant specification increased from 10 to 12. As in 2024/25, six ICBs said a service specification was in development, while the number reporting only a partial specification fell from three to one.

Overall, these shifts are modest and reinforce that evidence gaps remain widespread, with the number of ICBs unable to provide a relevant service specification increasing over the past year.

[viii] Cornwall and Isles of Scilly ICB claimed in its response that it does possess a relevant service specification but was unable to provide it.

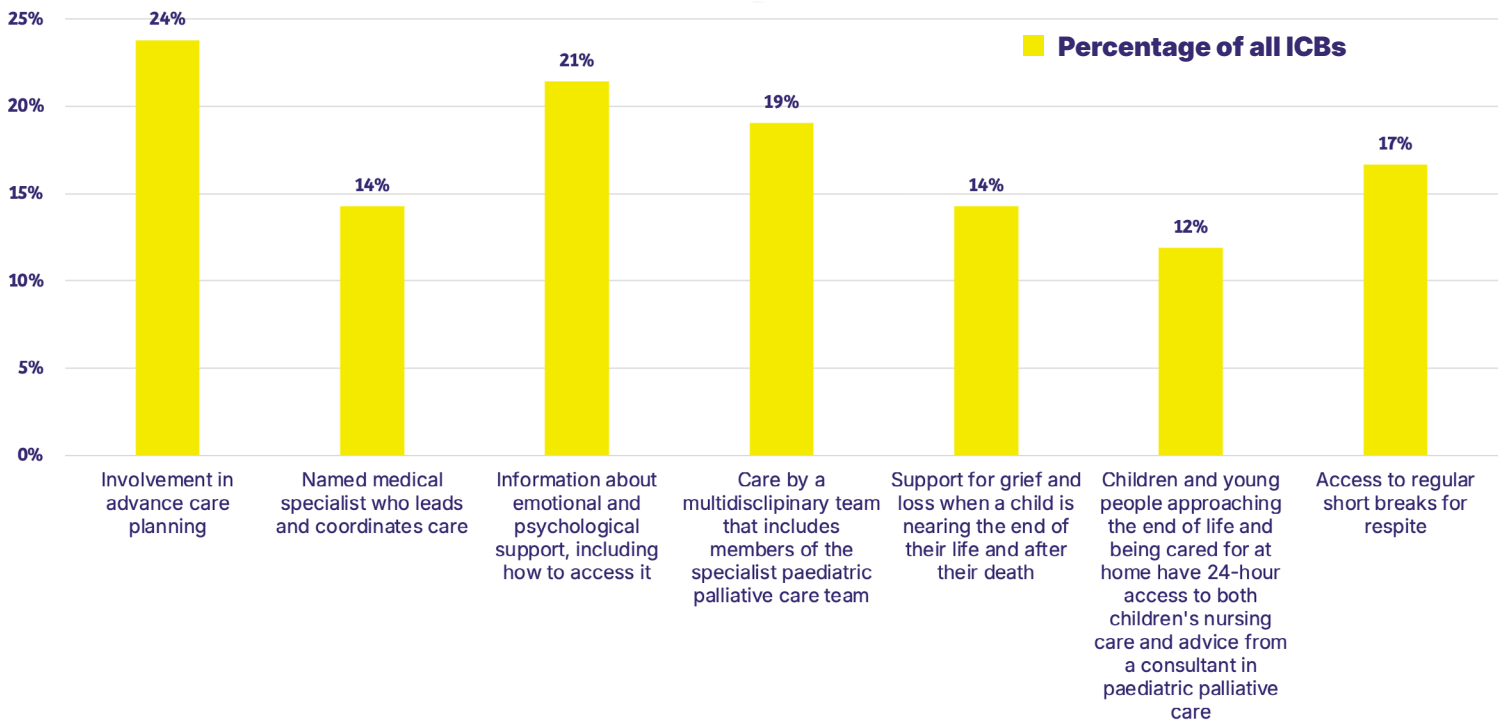
The extent to which ICBs possess a service specification for children's palliative care: 2024/25 vs 2025/26



Looking across the individual quality standards, the picture becomes even more troubling. Many ICBs reported that they were meeting national quality standards but were unable to provide documentation showing how these requirements were specified, monitored or funded.

For example, a quarter of ICBs (24%, 10 ICBs) claimed they commissioned services that ensured family involvement in advance care planning yet provided no evidence to support this. Likewise, one fifth of ICBs (19%, 8 ICBs) reported commissioning services that ensured access to a multidisciplinary team including members of the specialist paediatric palliative care team but were unable to supply a service specification or similar supporting evidence.

The extent to which ICBs were able to evidence claims they commissioned in line with a particular quality standard



This inconsistency between what ICBs say they are commissioning and what can be evidenced raises two important concerns. First, it suggests that a considerable amount of commissioning activity in children's palliative care may be informal or based on historic arrangements rather than structured, transparent commissioning processes.

Second, it indicates a wider weakness in accountability. If nearly half of all ICBs cannot evidence what they say they are commissioning, then neither families nor national or regional oversight bodies can be confident that services are being delivered equitably or in line with statutory duties.

Despite these substantial evidence gaps, it is important to acknowledge that commissioning does not always correlate directly with service provision. In other words, the absence of a clear service specification does not necessarily mean there are no services in a local area meeting the required standard.

For example, in West Yorkshire, despite the ICB not possessing a service specification, families who have accepted a referral are still able to access 24/7 end of life care at home, with Martin House Children's Hospice delivering round-the-clock medical advice and Forget Me Not Children's Hospice providing 24/7 nursing support.

Similarly, in Kent and Medway, despite the lack of a formal service specification, the presence of an established Managed Clinical Network (MCN) has enabled acute trusts,

community teams, hospices, tertiary centres and voluntary sector partners to come together to collectively deliver substantial elements of palliative and end of life care.[ix]

Despite these examples, service specifications remain essential for ensuring transparency, consistency and oversight. Without clear service specifications, ICBs lack the defined commissioning requirements needed to measure outcomes, ensure quality and drive improvement.

Crucially, the lack of a service specification leaves providers without a clear contractual framework, increasing the risk that critical elements of care are delivered inconsistently or reliant on goodwill rather than guaranteed provision. From a clinical governance perspective, the absence of clearly defined service specifications also creates risks around accountability, escalation pathways, workforce competencies, clinical supervision and consistency of care delivery across organisations.

Loss of managed clinical network funding risks progress

As seen in Kent and Medway, managed clinical networks (MCNs) often sit at the heart of efforts to improve children's palliative care across many areas.

By bringing together health professionals and organisations from primary, secondary and tertiary care, MCNs are well-placed to support services to operate in a coordinated and joined up way that is not constrained by existing organisational or professional boundaries. In turn, this strengthens partnership working, enhances service delivery and improves equity of care.[20]

The importance of MCNs is reinforced by the NICE clinical guidelines published in 2016, which recommended MCNs as the strategic mechanism for planning and delivering high quality palliative and end of life care for infants, children and young people with life shortening conditions. Specifically, the guidelines emphasise that services supporting children and young people approaching the end of life at home should be based on MCNs, with collaboration on care planning and service delivery at their core.[21]

Despite this, financial pressures have led many ICBs to withdraw their funding for networks, including Kent and Medway. This is particularly evident in the East Midlands where the network has been informed that ICB funding will cease from April 2026.

Since its establishment in 2022, the East Midlands MCN has made remarkable progress in improving palliative care for babies, children and young people with life-threatening conditions, life-shortening conditions or with severe medical complexity and their families across the region. The network has:

- Provided a vital forum for joined-up working across systems, reducing fragmentation and supporting consistent practice.

[ix] The Rapid Discharge Flow Chart and Investment Framework documents included in the appendices illustrate the extensive roles, responsibilities and clinical pathways are being delivered in practice, even where they are not underpinned by formal commissioning arrangements.

- Established regular clinical networks and oversight groups to identify gaps, drive quality and align improvement efforts.

- Delivered extensive training to reduce professional isolation and strengthen specialist skills.

- Piloted a 24/7 access-to-specialist-advice model that reduced hospital admissions and freed up GP, ambulance and hospital capacity.

- Supported regional progress toward meeting NICE guidelines and informed the development of cases for commissioned services and workforce investment.

The decision to withdraw ICB funding therefore places significant progress at risk. Representatives from the network have highlighted the likely consequences of this decision:

> "The removal of this coordinating function presents a risk of fragmentation across pathways, reduced consistency in care delivery, and loss of collective oversight of gaps and pressures within services.
>
> "There are also specific workforce risks. These include increased professional isolation for specialist nurses, reduced opportunities for shared education and skills development, challenges to succession planning, and potential impacts on recruitment and retention within an area of care that is already difficult to staff.
>
> "In addition, the absence of a system-level forum risks the loss of valuable workforce intelligence, shared learning, and relationships that have supported quality improvement and collaborative responses to emerging challenges."
>
> **- East Midlands Children and Young People Palliative Care Operational Delivery Network**

The withdrawal of funding for MCNs could also push services further away from meeting national standards set out in NICE guidance and from achieving the NHS 10-year plan's ambition to support more children to be at home at the end of life.

With additional ICBs across the country withdrawing funding from their MCNs, there is a real danger that the progress made in recent years to join up services, improve care and strengthen support for families could be reversed.

Recommendations for the Modern Service Framework

Through this report, we have demonstrated the significant variation that persists in the commissioning of children's palliative care across England, even where national quality standards set out clear expectations for commissioning bodies. Although commissioning activity does not always equate directly to service provision, the gaps identified at an ICB level present a major barrier preventing children with serious illness and their families from accessing the care and support they need.

The frequent absence of service specifications or similar documentation also highlights the different approaches taken by ICBs in commissioning children's palliative care. In many cases, this emphasises the vital role that managed clinical networks play in coordinating services and enhancing quality of care for families.

In recognition of these systemic challenges, the government has committed to developing a Modern Service Framework (MSF) for all-age palliative and end of life care. Aligned with the ambitions of the 10-Year Health Plan, ministers intend to use the MSF to consider contracting and commissioning arrangements as part of the broader shift towards strategic commissioning and address the unwarranted variation in access and quality of care.[22]

In June 2026, the government published an interim update on the MSF, outlining five working sub-goals that have been identified and a series of immediate actions intended to begin improving palliative and end of life care.[23] While the interim update was welcome, we are concerned that the overarching palliative and end of life care goal no longer specifically references babies, children and young people.

While just using the term 'person' could imply an all-age approach, history suggests that many local systems assume palliative and end of life care is just for older adults. Without a clear and explicit requirement to consider babies, children and young people from the outset, there is a real risk that their needs will be overlooked in commissioning decisions.

If the MSF is to be a success, it must therefore ensure the distinct needs of children and young people with life-threatening or life-shortening conditions or with severe medical complexity and their families, are fully recognised and not overshadowed by an all-age approach. Specifically, the framework must also commit to targeted action that addresses the inconsistencies in commissioning and secures a sustainable future for paediatric palliative care managed clinical networks.

This report therefore recommends that:

1. The government should ensure babies, children and young people are specifically mentioned in the wording of the government's overarching palliative and end of life care goal within the Modern Service Framework (MSF).

2. The government examines whether children's palliative care would be more effectively commissioned at a national or regional level to create economies of scale and reduce variation.

3. The Department of Health and Social Care (DHSC) considers a model in which specialist paediatric palliative care, as defined in the specialist tier of NHSE's children's palliative care service specification, is commissioned at a regional or national level to reduce variation and improve accountability.

4. DHSC directs ICBs to work with neighbouring ICBs in their region to commission targeted and universal tiers of children's palliative care as set out in NHSE's service specification.

5. The government establishes clear accountability mechanisms to underpin the MSF and ensure its implementation, including actions that will be taken if ICBs do not meet the required expectations.

6. The Secretary of State for Health and Social Care mandates the Care Quality Commission (CQC) to assess the extent to which ICBs are commissioning children's palliative care in line with national quality standards.

7. DHSC links commissioning responsibilities of ICBs to guaranteed funding streams, preventing unfunded mandates and improving service sustainability.

8. DHSC promotes mechanisms for sharing best practice and innovation between ICBs, supporting the replication of effective commissioning models.

9. DHSC and the Department for Education encourage joint commissioning across health, social care and education to deliver integrated support for children with serious illness and their families.

10. The government provides ringfenced funding, that increases in line with inflation, to secure the future operation and sustainability of paediatric palliative care managed clinical networks.

11. DHSC and NHS England should establish a national outcomes and assurance framework for children's palliative care commissioning, including measures relating to access to 24/7 support, place of death, advance care planning, symptom management, workforce capacity and family experience.

By ensuring these actions are taken, the government and local systems can begin to address the many inconsistencies in children's palliative care commissioning across England. In doing so, they can then help to ensure children with serious illness and their families receive the high-quality care and support they need, when and where they need it.

Action to bring about a more sustainable funding model and workforce for children's palliative care is also vital. As we lead our sector to develop a whole-system vision for the future of UK children's palliative care, we will produce proposals to enable the government and the NHS to work with providers to make sure they have the resources they need to deliver the MSF and achieve a system which truly puts families at the centre.

Appendices

Appendix 1: ICB responses to our FOI request

NHS Bath and North East Somerset, Swindon and Wiltshire Integrated Care Board

NHS Bedfordshire, Luton and Milton Keynes Integrated Care Board

NHS Birmingham and Solihull Integrated Care Board

NHS Black Country Integrated Care Board

NHS Bristol, North Somerset and South Gloucestershire Integrated Care Board

NHS Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board

NHS Cambridgeshire and Peterborough Integrated Care Board

NHS Cheshire and Merseyside Integrated Care Board

NHS Cornwall and The Isles of Scilly Integrated Care Board

NHS Coventry and Warwickshire Integrated Care Board

NHS Derby and Derbyshire Integrated Care Board

NHS Devon Integrated Care Board

NHS Dorset Integrated Care Board

NHS Frimley Integrated Care Board

NHS Gloucestershire Integrated Care Board

NHS Greater Manchester Integrated Care Board

NHS Hampshire and Isle of Wight Integrated Care Board

NHS Herefordshire and Worcestershire Integrated Care Board

NHS Hertfordshire and West Essex Integrated Care Board

NHS Humber and North Yorkshire Integrated Care Board

NHS Kent and Medway Integrated Care Board

NHS Lancashire and South Cumbria Integrated Care Board

NHS Leicester, Leicestershire and Rutland Integrated Care Board

NHS Lincolnshire Integrated Care Board

NHS Mid and South Essex Integrated Care Board

NHS Norfolk and Waveney Integrated Care Board

NHS North Central London Integrated Care Board

NHS North East and North Cumbria Integrated Care Board

NHS North East London Integrated Care Board

NHS North West London Integrated Care Board

NHS Northamptonshire Integrated Care Board

NHS Nottingham and Nottinghamshire Integrated Care Board

NHS Shropshire, Telford and Wrekin Integrated Care Board

NHS Somerset Integrated Care Board

NHS South East London Integrated Care Board

NHS South West London Integrated Care Board

NHS South Yorkshire Integrated Care Board

NHS Staffordshire and Stoke-On-Trent Integrated Care Board

NHS Suffolk and North East Essex Integrated Care Board

NHS Surrey Heartlands Integrated Care Board

NHS Sussex Integrated Care Board

NHS West Yorkshire Integrated Care Board

Appendix 2: ICB service specifications

Bath and North East Somerset, Swindon and Wiltshire ICB - Children's Palliative Care - Attachment 1_Redacted.pdf

Bath and North East Somerset, Swindon and Wiltshire ICB - Children's Palliative Care - Attachment 2_Redacted.pdf

Bath and North East Somerset, Swindon and Wiltshire ICB - Children's Palliative Care - Attachment 3_Redacted.pdf

Bedfordshire, Luton and Milton Keynes ICB - Attachment – Helen & Douglas Hospice specification.pdf

Bedfordshire, Luton and Milton Keynes ICB - Keech Milton Keynes Children Hospice specification.pdf

Birmingham and Solihull ICB

Black Country ICB - Acorns Service Specification 25_26.pdf

Bristol, North Somerset and South Gloucestershire ICB - 02 Question 8 - Service Specification - BNSSG Community Children Nursing and Psychology Service.pdf

Bristol, North Somerset and South Gloucestershire ICB - 03 Question 8 - Service Spec - CHSW.pdf

Bristol, North Somerset and South Gloucestershire ICB - 04 Question 8 - Service Spec - Jessie May.pdf

Cambridgeshire and Peterborough ICB - FOI 218a - CH09 Children's Community Nursing Service Specification_Redacted.pdf

Cambridgeshire and Peterborough ICB - FOI 218b - Children's Continuing Care and Training (1)_Redacted.pdf

Cambridgeshire and Peterborough ICB - FOI 218c - Community Childrens Nursing Service (2)_Redacted.pdf

Cambridgeshire and Peterborough ICB - FOI 218d - EACH 25_27 grant specification final v1.0_Redacted.pdf

Cheshire and Merseyside ICB - Children's emergency respite service specification.pdf

Cheshire and Merseyside ICB - NHSE specialist palliative and end of life care service specification.pdf

Cheshire and Merseyside ICB - Rapid response service specification.pdf

Devon ICB - Lot 1 Community Nursing FINAL.pdf

Dorset ICB - CYP Palliative and End of Life Service.pdf

Dorset ICB - PEoIC Service specification JH final 25.pdf

Frimley ICB - FINALISED Service Specification for 01.08.2025_redacted.pdf

Frimley ICB - The SPACE service (Shooting Star Hospice) SCHEDULE 2_redacted.pdf

Gloucestershire ICB - Children's Palliative Care – Attachment 1.pdf

Gloucestershire ICB - Children's Palliative Care – Attachment 2.pdf

Gloucestershire ICB - Children's Palliative Care – Attachment 3.pdf

Hertfordshire and West Essex ICB - East Anglia's Children's Hospices.pdf

Hertfordshire and West Essex ICB - Keech Hospice.pdf

Lancashire and South Cumbria ICB - Children's Palliative and End of Life Care Commissioning Framework - FINAL October 2024.pdf

Mid and South Essex ICB - Children's community integrated nursing service.pdf

Mid and South Essex ICB - Children's community specialist nursing service.pdf

Mid and South Essex ICB - Havens Hospices.pdf

Mid and South Essex ICB - Specialist Services.pdf

Norfolk and Waveney ICB.pdf

North East and North Cumbria ICB Q1 Specialist PEoLC Services CYP - Service Specification.pdf

North East and North Cumbria ICB Q3 CHIPS Childrens Holistic Integrated Palliative care final updated.pdf

North East London ICB - BCYP Hospice specification - 2023-24.pdf

North West London ICB - NHSE service spec-B1675-specialist-palliative-and-end-of-life-care-services-cyp.pdf

Northamptonshire ICB - Document 2 Short Breaks Specification.pdf

Northamptonshire ICB - NGH - Community Children's Nursing South Spec.pdf

Northamptonshire ICB - NGH - Community Paeds Service Spec_v0.1.pdf

Nottingham and Nottinghamshire ICB - 1A. SUB SPECIFICATION D.pdf

Nottingham and Nottinghamshire ICB - 1B. BASS CYP Healthcare Services 2017-19 redacted.pdf

Nottingham and Nottinghamshire ICB - 1C. 2021-24_Barnardos Service Spec.pdf

Nottingham and Nottinghamshire ICB - 1D. 2021-24_Rainbows Service Spec_New Format.pdf

Nottingham and Nottinghamshire ICB - 1E. Bluebell Wood Childrens Hospice Service Spec_Final.pdf

South West London ICB - Appendix A.pdf

South Yorkshire ICB - Appendix 1.pdf

Staffordshire and Stoke on Trent ICB.pdf

Suffolk and North East Essex ICB.pdf

Sussex ICB - Community Paeds Final V 7 _redacted.pdf

Sussex ICB - Specialist Nursing - V2 docx_redacted.pdf

Appendix 3: Other supporting evidence and documentation provided by ICBs

Cheshire and Merseyside ICB - palliative and end of life care programme delivery plan 2022-23.pdf

Hertfordshire and West Essex ICB - MCN Model.pdf

Kent and Medway ICB - Appendix 2 - Rapid Discharge flow chart.pdf

Kent and Medway ICB - Appendix 3 - Investment Framework - MCH (July 2025).pdf

Mid and South Essex ICB.pdf

North East and North Cumbria ICB - Q7 Stepping up for YP, parents, carers, professional.pdf

North East and North Cumbria ICB Q5 Paediatric-Palliative-Care-Guidelines-CHIPS-GNCH-Sept-2022.pdf

South East London ICB - Demelza guide-to-services-june-2024_web.pdf

South East London ICB - palliative-care-for-children - GSTT.pdf

Sussex ICB - NHS Sussex CYPCC policy.pdf

Appendix 4: ICB Ambitions for Palliative and End of Life Care self-assessments

NHS Bath and North East Somerset, Swindon and Wiltshire Integrated Care Board

NHS Black Country Integrated Care Board

NHS Bristol, North Somerset and South Gloucestershire Integrated Care Board

NHS Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board

NHS Cambridgeshire and Peterborough Integrated Care Board

NHS Devon Integrated Care Board

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NHS Herefordshire and Worcestershire Integrated Care Board

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NHS Humber and North Yorkshire Integrated Care Board Attachment 1

NHS Humber and North Yorkshire Integrated Care Board Attachment 2

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NHS Lincolnshire Integrated Care Board

NHS Mid and South Essex Integrated Care Board Attachment 1

NHS Mid and South Essex Integrated Care Board Attachment 2

NHS North Central London Integrated Care Board - Barnet

NHS North Central London Integrated Care Board - Camden

NHS North Central London Integrated Care Board - Enfield

NHS North Central London Integrated Care Board - Haringey

NHS North Central London Integrated Care Board - Islington

NHS North East and North Cumbria Integrated Care Board

NHS Northamptonshire Integrated Care Board

NHS Nottingham and Nottinghamshire Integrated Care Board

NHS South East London Integrated Care Board

NHS Suffolk and North East Essex Integrated Care Board

NHS Sussex Integrated Care Board

Appendix 5: Summary of ICB FOI response analysis

ICB:	**Question 1:** Does your ICB have a children's palliative care service specification?	**Question 2:** Has your ICB completed an Ambitions for Palliative and End of Life Care self-assessment?	**Question 3:** In your local area, does your ICB commission services which ensure infants, children and young people with a life-limiting or life-threatening condition and their parents or carers have opportunities to be involved in developing an advance care plan?	**Question 4:** In your local area, does your ICB commission services which ensure infants, children and young people with a life-limiting or life-threatening condition have a named medical specialist who leads and coordinates their care?	Question 5: In your local area, does your ICB commission services which ensure infants, children and young people with a life-limiting or life-threatening condition, their parents or carers and their siblings are given information about emotional and psychological support, including how to access it?	**Question 6:** In your local area, does your ICB commission services which ensure infants, children and young people with a life-limiting or life-threatening condition are cared for by a	**Question 7:** Do you have a children's palliative care service specification which states that siblings and parents or carers of infants, children and young people approaching the end of life should be offered support for grief and loss when their child is nearing the end of their life and after their death?	**Question 8:** In your local area, does your ICB commission services which ensure infants, children and young people approaching the end of life and being cared for at home have 24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care?	**Question 9:** In your local area, does your ICB commission services which ensure infants, children and young people with a life-limiting or life-threatening condition and their families have access to regular short breaks for respite?
	Children's palliative care service specification provided?	**Copy of self-assessment provided?**	**Is this standard explicitly accounted for in the supporting evidence?**	**Is this standard explicitly accounted for in the supporting evidence?**	**Is this standard explicitly accounted for in the supporting evidence?**	**Is this standard explicitly accounted for in the supporting evidence?**	**Is this standard explicitly accounted for in the supporting evidence?**	**Is this standard explicitly accounted for in the supporting evidence?**	**Is this standard explicitly accounted for in the supporting evidence?**

NHS Bath and North East Somerset, Swindon and Wiltshire Integrated Care Board	Y	Y	Y	P	P	P	P	Y	P
NHS Bedfordshire, Luton and Milton Keynes Integrated Care Board	Y	N	P	Y	P	P	P	P	P
NHS Birmingham and Solihull Integrated Care Board	Y	N	Y	P	P	P	Y	P	Y
NHS Black Country Integrated Care Board	Y	Y	Y	Y	P	P	Y	Y	Y
NHS Bristol, North Somerset and South Gloucestershire Integrated Care Board	Y	Y	Y	Y	Y	Y	Y	Y	Y
NHS Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board	Y	Y	Y	Y	Y	Y	Y	Y	Y
NHS Cambridgeshire and Peterborough Integrated Care Board	Y	Y	P	P	P	P	P	Y	Y

NHS Cheshire and Merseyside Integrated Care Board	Y	N	Y	Y	Y	Y	Y	Y	Y
NHS Cornwall and The Isles Of Scilly Integrated Care Board	N	N	M	M	M	M	M	M	M
NHS Coventry and Warwickshire Integrated Care Board	N	N	N	N	N	N	N	N	N
NHS Derby and Derbyshire Integrated Care Board	N	N	I	I	I	I	I	I	I
NHS Devon Integrated Care Board	P	Y	P	N	P	P	P	P	P
NHS Dorset Integrated Care Board	Y	Y	Y	Y	Y	P	Y	Y	Y
NHS Frimley Integrated Care Board	Y	N	Y	Y	Y	Y	Y	P	N
NHS Gloucestershire Integrated Care Board	Y	Y	Y	P	P	Y	Y	P	Y
NHS Greater Manchester Integrated Care Board	N	N	N	N	N	N	N	N	N

NHS Hampshire and Isle Of Wight Integrated Care Board	N	N	N	N	N	N	N	N	N
NHS Herefordshire and Worcestershire Integrated Care Board	N	Y	N	N	N	N	N	N	N
NHS Hertfordshire and West Essex Integrated Care Board	Y	Y	Y	Y	Y	P	Y	Y	P
NHS Humber and North Yorkshire Integrated Care Board	N	Y	N	N	N	N	N	N	N
NHS Kent and Medway Integrated Care Board	N	Y	M	M	M	M	M	N	M
NHS Lancashire and South Cumbria Integrated Care Board	P	Y	Y	Y	Y	P	Y	P	M
NHS Leicester, Leicestershire and Rutland Integrated Care Board	N	Y	I	I	I	I	I	I	I
NHS Lincolnshire Integrated Care Board	N	Y	N	N	N	N	N	N	N
NHS Mid and South Essex Integrated Care Board	Y	Y	Y	P	Y	P	Y	P	Y

NHS Norfolk and Waveney Integrated Care Board	Y	Y	P	P	P	P	P	P	Y
NHS North Central London Integrated Care Board	N	Y	N	N	N	N	N	N	N
NHS North East and North Cumbria Integrated Care Board	Y	Y	Y	Y	Y	Y	Y	Y	Y
NHS North East London Integrated Care Board	Y	N	Y	Y	P	Y	Y	Y	Y
NHS North West London Integrated Care Board	Y	N	Y	Y	Y	Y	Y	Y	Y
NHS Northamptonshire Integrated Care Board	N	Y	N	N	N	N	N	N	Y
NHS Nottingham and Nottinghamshire Integrated Care Board	Y	Y	P	N	Y	Y	Y	P	Y
NHS Shropshire, Telford and Wrekin Integrated Care Board	N	N	I	N	N	I	N	N	N
NHS Somerset Integrated Care Board	N	N	N	N	N	N	N	N	N

NHS South East London Integrated Care Board	N	Y	N	N	N	N	N	N	N
NHS South West London Integrated Care Board	Y	N	Y	Y	Y	Y	Y	Y	N
NHS South Yorkshire Integrated Care Board	Y	N	N	N	N	N	N	N	N
NHS Staffordshire and Stoke-On-Trent Integrated Care Board	Y	Y	Y	Y	Y	Y	Y	Y	N
NHS Suffolk and North East Essex Integrated Care Board	Y	Y	P	P	N	P	P	P	Y
NHS Surrey Heartlands Integrated Care Board	N	N	N	N	N	N	N	N	N
NHS Sussex Integrated Care Board	N	Y	N	N	N	N	N	N	N
NHS West Yorkshire Integrated Care Board	N	N	N	I	N	I	N	I	N

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