



# Short lives can't wait:

Children's hospice funding in 2024  
A report by Together for Short Lives



## Foreword

**Caring around the clock for a seriously ill child can be exhausting and isolating, and families can often feel pushed to their limits.**

For many families, being able to rely on the lifeline support from their local children's hospice is a lifeline. Providing care and support that spans a wide range of needs, children's hospices enable seriously ill children and their families to make the most of every moment that they have left together – be that years, months, or even just hours.

The value that children's hospices provide to our society goes without saying. Yet, we know that for far too long children's hospices across the UK have been confronted with financial challenges, particularly when it comes to the funding they receive from the state – that is, from governments, NHS bodies and local authorities

Grounded in the voices of children's hospices, this report shines a light on the current state of children's hospice funding in the UK. It is shocking to see that whilst inflation and the cost of recruiting and retaining staff has driven up costs, the funding children's hospices receive from the state has not kept up.

Children's hospices are therefore becoming increasingly reliant on public donations and their reserves. We wouldn't accept this for maternity care at the start of a child's life. Why should we accept this for palliative and end of life care?

Together for Short Lives is leading a movement to change this. Our purpose is to ensure that every child and family can access high quality children's palliative and end of life care, when and where they need it, in hospitals, children's hospices and in the community. We have a long-term vision for how we want to change the lives of children and families.

We have had incredible success in developing and funding programmes focused on reaching



families in communities where there is a higher prevalence of children with life-limiting illnesses and inconsistent service provision. Through our campaigning, we have influenced and been part of important work by the UK's governments, NHS bodies and provider organisations to improve care and support. And every day we are speaking to families who need emotional, financial, and practical support and helping them find it.

We are committed to playing our part in ensuring the per head spend by integrated care boards in England increases by 25%. In 2023, integrated care boards (ICBs) were spending on average £151 per child on children's hospice care. By 2027, we want ICBs to be spending an average of £189. We are committed to closing the £295 million shortfall in funding for children's palliative care, including securing the future of the children's hospice grant.

But we cannot do this alone. We need the public to support us now to help achieve these bold ambitions for children and families. We need the UK's governments, the NHS, and others to act urgently to make sure we have the workforce, funding and accountability in place to give families the care they need. Read our report to find out how you can help.

These children and families do not have time to waste. Together we must work to make sure that every child and young person has access to high quality, sustainable palliative care when and where they need it.

**Andy Fletcher**  
**Chief Executive, Together for Short Lives**

## Executive summary

- **Crucial services, including respite and end of life care, will be cut if the next UK Government fails to maintain the existing £25 million NHS England (NHSE) funding for children's hospices.**
- **Shockingly, local NHS and council funding for children's hospices – which was already patchy and unsustainable – is continuing to fall.**
- **Amid a year of high inflation and growing costs of recruiting and retaining skilled and experienced staff, children's hospices' costs are rising.**
- **As deficits grow, children's hospices are increasingly relying on their charitable income and reserves to provide vital care and support.**
- **Ministers across the UK – including any newly appointed following the general election – must act urgently to ensure seriously ill children and their families can access the crucial hospice and palliative care services they need.**

**Crucial services including respite and end of life care will be cut if the next UK Government fails to maintain the existing £25 million NHSE funding for children's hospices.**

The £25 million of funding that NHSE provides to children's hospices is a crucial and welcome contribution to the cost of providing care to children and families. On average, it accounts for approximately 16% of children's hospices' charitable expenditure.

Given how important it is, we are very concerned that the UK Government has not confirmed whether it will continue beyond 2024/25. Children's hospices have told us that, if the £25 million was not available from 2025/26 onwards, there would be a profoundly negative impact on lifeline care and support:

- **82% would cut or stop providing respite care or short breaks.**
- **70% would cut or stop providing emotional and/or psychological support.**
- **45% would cut the end of life care they provide.**

### Local NHS funding for children's hospices in England is falling

In 2023/24, children's hospices received, on average, nearly 10% less funding from ICBs compared to 2022/23 and over a third (31%) less funding when compared to 2021/22. In 2022/23, each children's hospice received an average of £524,278 from their local ICBs. However, in 2023/24, they received an average of £477,677.

## Since 2021/22 children's hospices received



Short Lives Can't Wait

Children's hospice funding in 2024

ICB funding represented about 11% of the charitable expenditure incurred by children's hospices in 2023/24, down from 13% in 2022/23.

On average, ICBs spent £149.15 for every case of a life-limiting or life-threatening condition among children and young people aged 0-24 in their local area.

However, the amounts spent by each ICB varied by as much as £366.42. Whilst Bristol, North Somerset and South Gloucestershire ICB spent the most with an average of £397.01 per child or young person, Northamptonshire ICB spent the least with an average of £30.59 per case.

These shocking figures show why NHSE's £25 million to children's hospices must continue – and why it should continue to be ringfenced solely for children's hospices.

Only two fifths (40%) of ICBs know how many children and young people accessed hospice care during 2023/24. Only a quarter (26%) know how many children and young people with life-limiting or life-threatening conditions in their area could benefit from palliative care.

### **Local council funding for children's hospices in England is falling**

Currently accounting for an average of just 2.6% of children's hospices' charitable expenditure, we have found that local authority funding for children's hospices in England has decreased by 26.1% from an average of £149,939.92 in 2022/23 to £110,767.56 in 2023/24.

Across all parts of the UK, a lack of long-term and sustainable statutory funding has resulted in children's hospices being stretched financially as they increasingly rely on their charitable income and reserves to provide this vital care and support.

### **Children's hospices are providing more care and support**

Since 2019/20, children's hospices across the UK have provided end of life care and symptom management to two fifths (41%) and nearly three quarters (72%) more children and young people respectively. Similarly, step down care has also been provided to two fifths (41%) more children and young people.

### **The cost of providing children's hospice care is rising**

Whilst children's hospices continue to provide vital care and support to seriously ill children and their families, recent years has seen inflation and the cost of recruiting and retaining skilled and experience staff soar.

As a result, children's hospices' costs are rising rapidly.

We have found that during 2023/24, children's hospices' charitable expenditure increased by 12%, rising from £4.1 million in 2022/23 to £4.5 million in 2023/24. When compared to 2021/22, children's hospices' charitable expenditure in England has increased by 15% from an average of £3.6 million.

Two thirds (66.7%) of children's hospices attributed their increased costs to higher energy prices and higher costs of consumables, over a half (63.9%) of hospices claimed the higher expenditure was due to an increase in activity, whilst over three quarters (86.1%) attributed the increase to higher costs of recruiting and retaining staff.

Recruiting from the same pool of staff as the rest of the NHS, in order to match the increased NHS salaries resulting from higher pay settlements in Agenda for Change roles, children's hospices are



having to find the funds from their local community in order to match these costs.

## **Over half of children's hospices reported net deficits in 2023/24 – with worse to come**

As a result of a lack of long-term and sustainable statutory funding coupled with the increasing costs incurred when providing lifeline care to seriously ill children and their families, over a half (54%) of UK children's hospices that responded ended the 2023/24 financial year with a net deficit. When extrapolated across all 39 children's hospice organisations in the UK, we estimate a total shortfall of £8,521,182.

Looking ahead to 2024/25, the picture gets even worse, with nearly three quarters (72%) of children's hospices forecasting a net deficit with the total shortfall across all 39 organisations estimated to reach just over £30 million.

## **A similar picture in Northern Ireland, Scotland, and Wales**

Looking at the other devolved nations, similar difficulties are being experienced. Whilst inflationary pressures are continuing to drive the increase in care costs, statutory funding for children's hospices across Northern Ireland, Scotland and Wales has not kept the pace.

In Northern Ireland, despite statutory funding increasing to just over £1.9 million in 2023/24, rising costs caused by inflationary pressures has resulted in a reduced number of beds at the children's hospice.

In Scotland, inflationary costs, increased NHS pay awards and the expansion of services to meet demand have increased CHAS' cost base. As a result, the £7 million of annual funding previously awarded by the Scottish Government now only amounts to 30% of CHAS' total expenditure – a shortfall of £3 million per year.

Similarly, in Wales, despite the previous £880,000 awarded to the children's hospices in 2022, inflationary pressures, including difficulties in recruiting and retaining staff stemming from the need to match increased Agenda for Change pay settlements has seen funding challenges exacerbate. As a result, the previous funding that was awarded no longer represents 21% of the hospices' care costs and as such is no longer sustainable.

## **The UK's governments need to act urgently**

We therefore call for the following urgent action to make sure that children's hospice care in England, Northern Ireland, Scotland, and Wales is funded in a way that is equitable and sustainable for the long-term:

### **England**

Following the general election, the next UK Government should:

- 1) Review the way in which children's hospice care is funded to ensure children's hospices are equipped to provide lifeline care and support to seriously ill children and their families for the long-term.
- 2) Commit to maintaining, ringfencing and increasing the £25 million NHS England funding for children's hospices by the rate of inflation – and returning it to being a centrally-distributed funding stream.

- 3) Hold ICBs to greater account for the way in which they commission children's palliative care.
- 4) Direct ICBs to work with neighbouring ICBs in their region to plan and fund key services.
- 5) Ensure local authorities have the funding they need to comply with their legal duty to provide short breaks to families of seriously ill children.

## Northern Ireland

- 1) Commit to providing additional and sustainable statutory funding to Northern Ireland Children's Hospice for the long-term. This funding should be sufficient to cover 50% of the costs incurred in providing lifeline care and support to children and their families.
- 2) Ensure that any additional and recurrent statutory funding that is awarded is tied to and increases in line with the rising costs caused by inflationary pressures.

## Scotland

- 1) Re-commit to providing additional and sustainable statutory funding to Children's Hospices Across Scotland (CHAS) for the long-term. This funding should be sufficient to cover 50% of agreed costs in providing lifeline care and support to children and their families.
- 2) Ensure that any additional and recurrent statutory funding that is awarded is tied to and increases in line with the rising costs caused by inflationary pressures.

## Wales

- 1) Commit to providing long-term, sustainable and fair funding to Tŷ Hafan and Tŷ Gobaith. This funding should be sufficient to cover at least 21% of the costs incurred in providing lifeline care and support to children and their families.
- 2) Ensure that any additional and recurrent statutory funding that is awarded is tied to and increases in line with the rising costs caused by inflationary pressures.

**If this action is not taken, seriously ill children and their families' access to crucial hospice and palliative care services like end of life care and short breaks could be put at risk.**

**Seriously ill children do not have time to wait for hospices to receive this reassurance.**



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# Introduction

Children's hospices across the UK provide vital care and support to children and young people with life-limiting and life-threatening conditions and their families. Whether it be through short breaks for respite, help with accessing the right services and support, or, for many families, supporting them through the loss of a child and beyond, children's hospices are a fundamental source of support for seriously ill children and their families.

Children's hospices offer great value for money. By providing palliative and end of life care to children with life-limiting and life-threatening conditions at home and in hospices, they relieve immense pressure off the NHS and local health and care systems.

To understand more about the current state of children's hospice funding across the UK, in April 2024, we asked all 39 children's hospice organisations how they were funded in 2023/24 and the impact this has had on the services they have been able to provide to seriously ill children and their families. We also asked how they expected this to change in 2024/25.

Having previously asked similar questions and published the findings in 2023,<sup>1</sup> not only have these findings revealed the current state of children's hospice funding, but they have also allowed us to examine how this has changed since 2022/23.

In total, 37 children's hospice organisations across the UK responded to our survey. Among the hospices that responded, we received responses from all children's hospices in the devolved nations of Northern Ireland, Scotland, and Wales.

In England, as part of children's hospices' funding is derived from integrated care boards (ICBs), in April 2024, we also issued a series of freedom of information (FOI) requests to all 42 ICBs. Similar to the FOI requests we issued in 2023,<sup>2</sup> we asked ICBs:

- 1) How much money they had spent on hospice care for children and young people with life-limiting or life-threatening conditions between 6 April 2023 and 5 April 2024. We asked them to provide a total, in addition to a breakdown of funding per children's hospice organisation.
- 2) How many children and young people with life-limiting or life-threatening conditions who lived in their integrated care board footprint accessed hospice care between 6 April 2023 and 5 April 2024. We asked them to provide a total, in addition to a breakdown of funding per hospice organisation.
- 3) How many children and young people with life-limiting or life-threatening conditions who lived in their integrated care board footprint could benefit from children's hospice care.
- 4) How much money they plan to spend on hospice care for children and young people with life-limiting or life-threatening conditions between 6 April 2024 and 5 April 2025. We asked them to provide a total, in addition to a breakdown of funding per children's hospice organisation.

In response to our FOI request, 40 out of the 42 ICBs in England responded to our request. These FOIs have helped us to further establish how each ICB funded children's hospices in 2023/24 – and how ICBs are planning to fund them in 2024/25.

This report therefore outlines the findings from our survey and these FOI requests, before setting



out the action we call on governments and health and care systems across the UK to take to ensure children's hospices are funded in a way that is equitable and sustainable for the long-term.

## **Terms used in this report**

When referring to ICB funding in this report, we wish to reflect the fact that, during 2022/23, clinical commissioning groups (CCGs) were abolished and replaced by integrated care boards (ICBs) as the organisations legally responsible for commissioning NHS-funded care in England.

Where the term children's hospice is used in this report, it means children's hospice organisation. Averages have been calculated as a mean of the total responses to a particular question.

Finally, throughout the report the terms 'charitable expenditure' and 'care costs' are used interchangeably to refer to the costs incurred in providing lifeline palliative and end of life care to children and young people with life-limiting and life-threatening conditions and their families.



## Corey and Parker's story

For Karina and Jason, having a disabled son turned them from first-time parents into full-time carers. Having their second disabled child was more than they could manage alone.

Thankfully, Claire House Children's Hospice has helped the mum and dad-of-four to smile with their children again.

And, thanks to the hospice's life-changing support, the family can cherish precious last moments with their eldest boy Corey.

### Needing round-the-clock care

"Corey's my little monkey. He was born prematurely at 25 weeks and he's had a lot of problems. He needs pain relief all the time, constant movement and one-to-one assistance," says mum Karina.

Weighing just 11lb 14oz, Corey was reliant on oxygen at birth. At 18 months old, he was diagnosed with cerebral palsy.

Shortly after Corey turned two, his sister Georgie was born without any complications.

It was only after Karina and Jason's third child, Parker, was born with complex medical needs they realised they could no longer cope on their own.

"Parker's condition meant that, like his older brother, he needed round-the-clock care," says Karina.

"You become a nurse overnight. You go from being mum to a carer and there is no time to be just a mum again.

"We weren't getting any sleep and would argue over who had the most sleep.

"For us, it was just about accepting that it's not a weakness to admit we needed help."



## Being a parent, not a carer

After receiving support from Claire House, the couple joined the boys during their first hospice stay to help them settle in.

“It was great because we could go downstairs to see the boys having fun and then go back upstairs.

“You can enjoy time with your children without having to worry about medication being on time, feeds being done, their pads changing, their movement.

“So, I got to smile with my children again. I got to enjoy playing games and being with them as a parent, not a carer. It was lovely.”

And the boys agree Claire House is wonderful.

“They both love it when they go to Claire House,” Karina explains. “Parker thinks he’s going on holiday. He’ll be painting or covered in goo. The children go to Chester Zoo on trips. We don’t have the space at home to do half the things Claire House do.”

Jason adds: “Having Claire House’s support has meant we’ve been able to spend time with Georgie, welcome our fourth child Lottie and get some much-needed rest.”

Now aged 14, Corey’s health has deteriorated, and he is now receiving palliative care.

## Making the most of every moment, together

Karina says: “It’s not nice because you’re grieving for your child while he’s still here. We just don’t know how long we’ve got with Corey.

“The ironic thing is he’s always smiling which keeps us going. We just have to make the most of the time we’ve got.

“Georgie has a fantastic bond with Corey. She doesn’t see a disability; she just sees her brother.

“No 11-year-old should have to know she might lose her brother, but she’s aware of the reality and she does well.”

In addition to Corey and Parker’s care, Claire House supports the whole family. The hospice offers the parents a chance to step back from their caring roles, take time for themselves and connect with people in similar circumstances.

“They don’t just help the boys, they help the girls and us as a family”, explains Jason.

“The Claire House sibling events are brilliant. They also put things on for us, so I play golf with the dads and meet other parents that have disabled children.”

Karina agrees Claire House is a valuable lifeline.

She says: “We would be totally lost without Claire House. Back to being tired, not being parents, just being carers. That’s not a life for us and not a life for the children.”

# Statutory funding for children's hospices in England

In England, we have found that approximately a third (30.2%) of children's hospices' charitable expenditure is paid for by the state - that is, from governments, NHS bodies and local authorities. The proportions of children's hospices' charitable expenditure that each funding source accounts for is as follows:<sup>i</sup>

- NHSE funding for children's hospices – 16.17%
- ICB funding – 11.41%
- Local authority funding – 2.64%

Despite this, we have found that inflationary pressures and an ongoing lack of long-term and sustainable statutory funding has meant the proportion of charitable expenditure that is covered by the state has decreased by 3.1% since 2022/23.

As such, children's hospices are having to increasingly rely on their charitable income and reserves in order to provide lifeline care and support to seriously ill children and their families.

Whilst positive progress has been made in recent years with regards to children's hospices' statutory funding, namely through the continuation of the NHSE Children and Young People's Hospice Grant and the NHSE match funding scheme, there is still an urgent need for a more equitable and sustainable solution when it comes to statutory funding.

## NHS England funding for children's hospices

In July 2019, NHSE decided to increase the Children's Hospice Grant to £25 million by 2023/24 and ringfence this money specifically for children's hospices. The Children's Hospice Grant amounts during this period have been:

- 2020/21: £15 million
- 2021/22: £17 million
- 2022/23: £21 million
- 2023/24: £25 million

This additional NHS funding for children's hospices has been very welcome and has come at a time when they have been providing care and support to a growing number of seriously ill children and families who have increasingly complex needs.

Following a campaign by Together for Short Lives, children's hospices and the public, the Minister of State for Social Care, Helen Whately committed to renewing the grant for 2024/25. In February 2024, it was then confirmed that the funding would be disseminated via ICBs in line with the wider move to a devolved NHS.

Since then, NHS England has written to ICBs and children's hospices to let them know:

- How much funding would be allocated to each ICB to distribute.
- What each children's hospice should receive from each ICB.
- What the process for releasing funding to ICBs would be.

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<sup>i</sup> Please see appendix A for a graph illustrating a breakdown of the proportion of charitable expenditure of children's hospices in England that is paid for by the state.



Following this letter, every ICB has now submitted its return to NHSE and has identified a Children and Young People's Palliative and End of Life Care Lead. As a result, children's hospices should now be able to access this funding for 2024/25.

Whilst this commitment is welcome and we are pleased to see steps now being taken to distribute the funding to children's hospices, we are very concerned that this funding stream is yet to be confirmed for years beyond 2024/25.

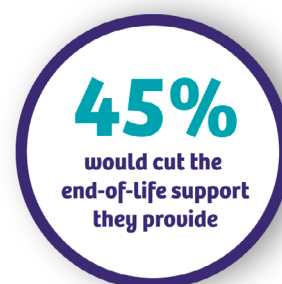
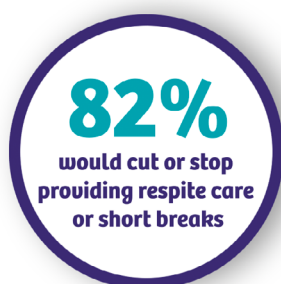
Of the 32 children's hospices in England that provided us with their NHSE funding allocations for 2023/24, the average amount of funding received equalled £667,123.59. This NHSE funding stream therefore accounts for approximately 16% of children's hospices' charitable expenditure, making it a vital source of funding for the sustainability of children's hospices.

**“Without the current Children's Hospice Grant our services would not be sustainable.”**  
**Butterwick Children's Hospice**

The importance of this funding becomes even more evident when considering the impact it has on the palliative care that is provided to serious ill children and their families. In response to our survey, children's hospices told us that if this funding was not available beyond 2024/25, the following action would have to be taken:<sup>ii</sup>

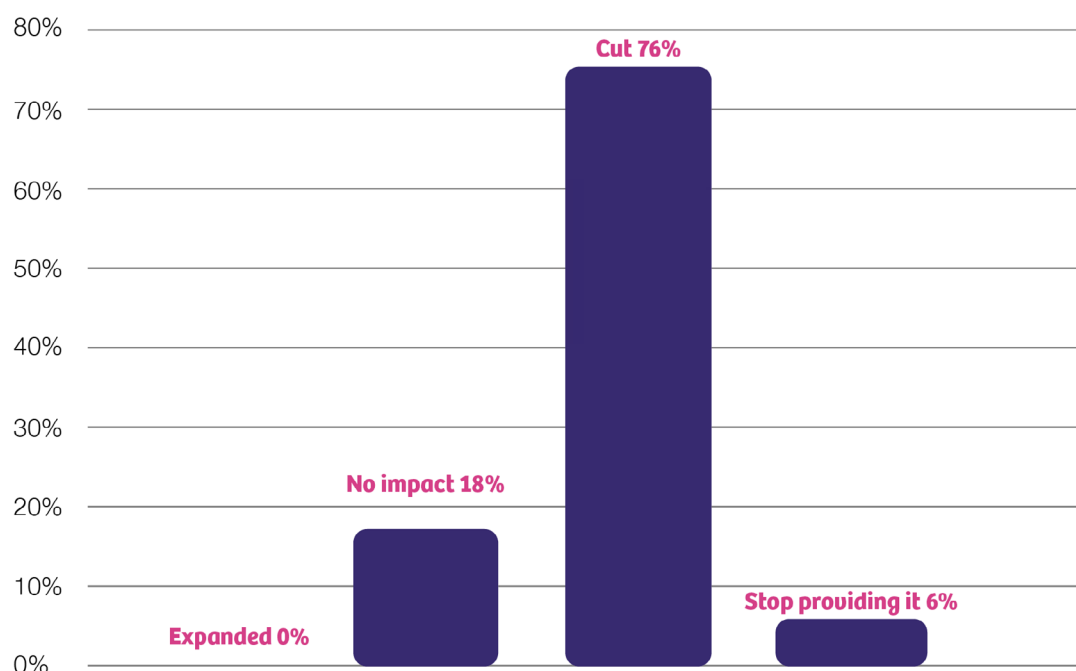
- 82% would cut or stop providing respite care or short breaks.
- 70% would cut or stop providing emotional and/or psychological support.
- 45% would cut the end of life care they provide.
- 42% would cut their symptom management provision.
- 64% would cut or stop providing hospice at home services.
- 42% would cut or stop providing step down care.

## If the next Government fails to back the **£25m NHSE** **funding for** **children's hospices...**



<sup>ii</sup> Please see appendix B for a graph showing all the action that would be taken if the NHSE funding for children's hospices is not maintained for years beyond 2024/25.

### The impact on short breaks for respite if the NHSE funding for children's hospices was not available from 2025/26 onwards



It is particularly concerning to see that the majority of children's hospices would be forced to cut or stop providing respite care or short breaks if this funding was not available from 2025/26 onwards.

Respite care is invaluable to families of seriously ill children. According to one study published recently, the development of respite services can help reduce the risk of emotional exhaustion and mental health problems.<sup>3</sup>

Cutting respite care would therefore have a profoundly negative impact on families. Research published in 2021 has shown that mothers of seriously ill children are significantly more likely to experience common and serious physical and mental health problems. It has also been shown that the risk of premature death is 50% higher for mothers of a child with a life-limiting condition than mothers of children with no long-term health conditions.<sup>4</sup>

Cutting or stopping respite care could therefore further exacerbate these inequities.

The value of respite care is therefore significant.

Not only would these cuts have an impact on families, but they would also negatively impact the NHS and wider health and social care system.

**"We are the only children's hospice in the East Midlands. So, reducing any services would have a greater impact on hospital bed stays, community support and being passed from one service to another."**

**Rainbows Hospice for Babies, Children and Young People.**

**“We have significant impact on the wider health service. We provide symptom management stays for children and young people that would otherwise be in an intensive care bed in their local acute hospitals. We also support community teams to oversee specialist palliative care of children in the community. We provide bereavement support for very emotionally distressed parents and family members who would otherwise likely be accessing mental health support from local statutory services.”**

**Helen and Douglas House**

**“We support our regional and/ or local health and social care systems by providing 24/7 end of life specialist care at home and in the hospice, therefore enabling choice of place of death. With symptom management we support hospital admission avoidance. Step down care which facilitates earlier discharge from hospital.”**

**Haven House Children’s Hospice**

It is therefore vital that the next UK Government commits to maintaining, ringfencing and increasing the £25 million NHS England funding for children’s hospices by the rate of inflation – and returning it to being a centrally-distributed funding stream.

As mentioned, 2024/25 will see this NHSE funding disseminated via ICBs. Whilst we believe it is right that ICBs are responsible for understanding the needs of seriously ill children and families within their local populations and therefore should be responsible for allocating some NHS funding to children’s hospices, we are concerned that devolving all NHS children’s hospice funding to ICBs could exacerbate the existing inequity in funding.

Seriously ill children represent a small but complex population compared to other groups that ICBs need to plan and fund services for. As a result, in many cases, ICBs have not prioritised work to commission children’s palliative care. This has been the case even when funding has been available for clinical commissioning groups (CCGs, which were abolished and replaced by ICBs in July 2022) and ICBs from the Government and NHSE, such as the NHS Long Term Plan children’s palliative care match funding, which not all CCGs – and subsequently ICBs – have chosen to access.

The non-recurrent £25 million funding for children’s and adult hospices in 2019/20 announced by the Prime Minister in August 2019 is another case in point. The Government and NHSE decided that the money was to be spent locally, improving care for patients as soon as possible. CCGs were asked to identify any gaps in local palliative care provision and put in place service development plans to address this identified need. The money was not ringfenced and was added to CCGs’ resource allocations later in 2019. CCGs were only given an expectation by NHSE that they work collaboratively to assign the money to hospices and palliative services within their sustainability and transformation partnership (STP) footprint.



## Local integrated care board funding

### Insufficient funding from ICBs

As mentioned, ICBs are also responsible for allocating NHS funding to children's hospices. In response to our survey, 32 children's hospice organisations in England told us about their local NHS funding.

2023/24 marked the final year of the NHSE match funding scheme. This scheme was committed to in the NHS Long Term Plan and made up to £7 million of match funding available to ICBs for children's palliative care, including children's hospice services. The £7 million available in 2023/24 is an increase on the £5 million of match funding that was available during 2022/23.

Despite this increase in funding available to ICBs, we have found that children's hospices received, on average, nearly a tenth (9%) less funding from ICBs in 2023/24 when compared to the funding they received from ICBs in 2022/23.

In 2022/23, children's hospices received an average of £524,277.64.<sup>iii</sup> However, in 2023/24, they received an average of £477,676.59.<sup>iii</sup>

Overall, this represents about 11% of the charitable expenditure incurred by children's hospices, down from 13% in 2022/23. In other words, for every £9 spent on supporting seriously ill children and their families, only £1 was paid for by ICBs.

When comparing to the average funding children's hospices received from ICBs in 2023/24 and from CCGs/ICBs in 2021/22, we have found this particular funding stream has decreased by 31% over the course of these two years.

**"We have requested an uplift of 6% from April 2024 in line with staffing cost increases. It has not yet been agreed by Health and Social care (who split the cost of care provided). However, we have agreed to an open book accounting exercise to demonstrate the cost to commissioners, and this will hopefully allow the uplift to be agreed. At this point health has only offered an 0.6% uplift."**

#### St Oswald's Hospice

Even then, we have found local NHS funding to vary in terms of the proportions of children's hospices' charitable expenditure that it represents.

Nearly half (47%) of all children's hospices that responded received less than 10% of their charitable expenditure from ICBs.

Almost one quarter (22%) of the children's hospices that responded received less than five percent of their charitable expenditure from ICBs.

Only one children's hospice received 30% or more of their charitable expenditure from ICBs.

Comparing to 2022/23, we have found that the number of children's hospices receiving less than five percent or 10% of their charitable expenditure from ICBs has increased whilst the number of hospices receiving 30% or more of their charitable expenditure from ICBs has decreased.

<sup>iii</sup> Please see appendix C for a graph illustrating the change in mean local NHS funding for children's hospices across England.

When asked about their predictions for 2024/25, on average, children's hospices expect their ICB funding to increase by three percent to £492,206.76. Nearly a half (44%) of hospices expect it to increase whilst over a quarter (26.5%) expect it to decrease and over two fifths (23.5%) expect it to remain at current levels. Two children's hospices did not answer this question.

## Variance in ICB funding

In addition to our survey, in April 2024, we also issued a series of FOI requests to all NHS integrated care boards in England. Similar to the FOI requests we submitted to ICBs in May 2023, we asked ICBs:

1. How much money they had spent on hospice care for children and young people with life-limiting or life-threatening conditions between 6 April 2023 and 5 April 2024. We asked them to provide a total, in addition to a breakdown of funding per children's hospice organisation.
2. How many children and young people with life-limiting or life-threatening conditions who lived in their integrated care board footprint accessed hospice care between 6 April 2023 and 5 April 2024. We asked them to provide a total, in addition to a breakdown of funding per hospice organisation.
3. How many children and young people with life-limiting or life-threatening conditions who lived in their integrated care board footprint could benefit from children's hospice care.

Some ICBs were also able to tell us how much money they planned to spend on hospice care for children and young people with life-limiting or life-threatening conditions between 6 April 2024 and 5 April 2025.

In total, 40 out of 42 ICBs responded to our request.

To ensure a consistent approach, we analysed the FOI responses on the basis of what ICBs have told us. As many ICBs told us that their financial year ran from 1 April 2023 to 31 March 2024, we also included responses provided within this timeframe in our analysis.

From these FOI requests, we have found that in 2023/24, on average, ICBs spent £149.15 for every case of a life-limiting or life-threatening condition among children and young people aged 0-24 in their local area.<sup>iv</sup> Despite the increased funding available to them through the NHSE match funding scheme, our FOI requests have revealed that the average amount spent by ICBs per child or young person over the past year has decreased by one percent from £151.03.<sup>6</sup>

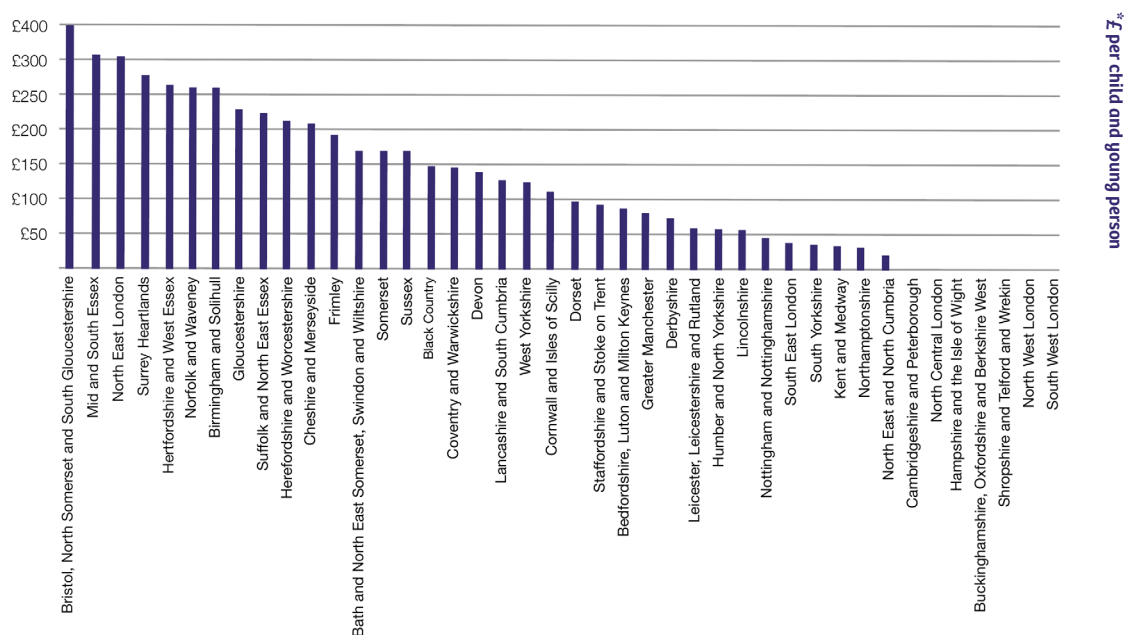
Similar to what we have found previously, the amounts spent by each ICB continue to vary significantly. This year, we have found ICB spending to vary by as much as £366.42.<sup>v</sup>



<sup>iv</sup> Note: North West London ICB and South West London ICB were not able to tell us about the amounts spent on hospice care for children and young people aged 0-18. Cambridgeshire and Peterborough ICB, Hampshire and Isle of Wight ICB and North Central London ICB were only able to provide an amount spent on services for children aged 0-18 years old. As the remaining ICBs told us about the amount spent on services for children and young people aged 0-24 years old, we have therefore omitted these ICB's responses from our analysis.

<sup>v</sup> Please see appendix D for the full data obtained from these FOI requests.

## 2023/24 total spending by ICBs on children's hospice care per number of cases of life-limiting and life-threatening conditions among children and young people aged 0-24 in ICB area\*



Whilst Bristol, North Somerset and South Gloucestershire ICB spent the most with an average of £397.01 per child or young person, Northamptonshire ICB spent the least with an average of £30.59 per case.<sup>vi</sup>

Whilst the extent to which ICB spending varies is not as great as what we found in 2022/2023, the upper limit of the range in 2023/24 was significantly lower. In 2022/23, we found Norfolk and Waveney to be the highest spending ICB with an average of £511 per case.<sup>7</sup> However, in 2023/24, Norfolk and Waveney ICB spent 49% less with an average of £260.81 per child or young person.

Here, it is important to note that, at any one time, many children and young people with life-limiting or life-threatening conditions are relatively stable and will not need active care and support from a children's hospice. The funding that an ICB decides to allocate to a children's hospice will depend on the need for care and support, in addition to how local children's palliative care services are configured across hospital, community and children's hospice settings.

However, despite these factors, we do not believe that the extent to which funding varies between ICBs can be justified. If anything, the continued variance in local ICB spending on children's hospices reaffirms our concerns that devolving all NHS children's hospice funding to ICBs could exacerbate this inequity in funding even further.

**"In all honesty, the fragmented nature of devolved commissioning, with different ICBs moving at different paces, changing their staff, and having different attitudes to whether they should commission their local children's hospice to some extent or even at all, is chaotic."**

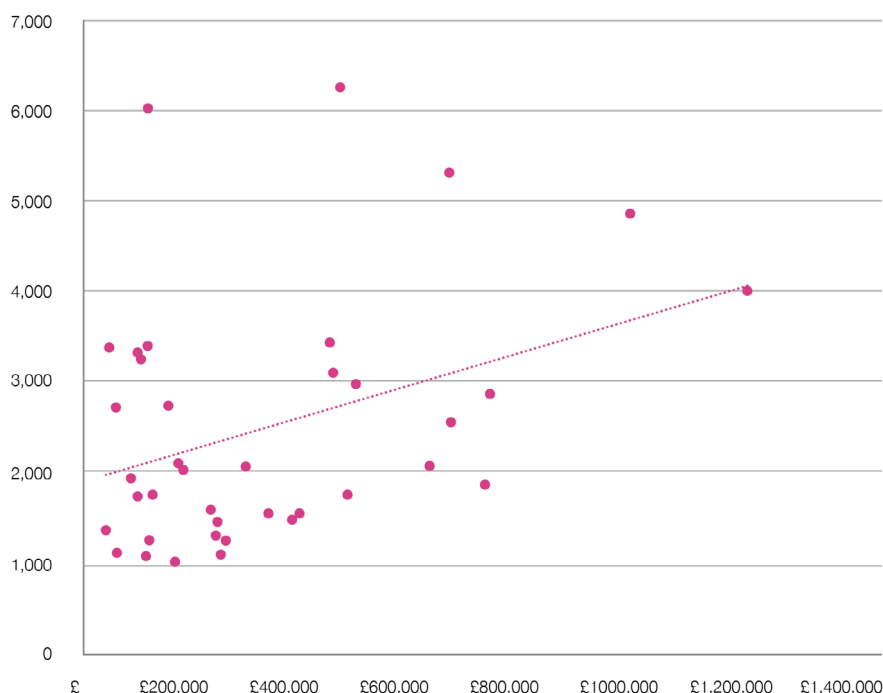
**Julia's House Children's Hospice**

<sup>vi</sup> Note: A number of ICBs were only able to provide partial data and therefore may not be entirely representative of the actual amount spent on children's hospice care by the ICB. The ICBs this applies to are as follows:

- NHS North East and North Cumbria ICB have not been able to provide us with a funding figure for children's hospices in the other places, we have therefore only included the figure for the North Cumbria place in our analysis.
- Kent and Medway ICB also provided a reduced figure. Whilst Ellenor also received funding from Kent and Medway ICB, the ICB was unable to split the funding between the children and adult services. As such, the amount spent on Ellenor hospice services was not provided.
- Leicester, Leicestershire and Rutland ICB told us that a further £2,458,611.15 was paid to LOROS Hospice who care for adults from age 18. As this amount could include those aged over 24 years, we have not included this figure in our analysis.



### Number of cases of life-limiting and life-threatening conditions (LLCs and LTCs) among children and young people aged 0-24 in ICB area



### Lack of local data held by ICBs

From our FOI request, we have also identified a lack of understanding among ICBs about the numbers of children accessing hospice care in their areas, as well as the numbers of children with life-limiting or life-threatening conditions that could benefit from palliative care.

We have found that only 17 (40%) of the ICBs that responded to our request were able to tell us how many children and young people accessed hospice care during 2023/24. Among those that were able to tell us about the number of children accessing hospice care, the average number was 285 children and young people per ICB.

Similarly, only 11 (26%) ICBs were able to tell us how many children and young people with life-limiting or life-threatening conditions in their area could benefit from palliative care.

This is particularly worrying given the legal duty placed on ICBs by the Health and Care Act 2022. Under the Act, ICBs are required to commission palliative care as they consider appropriate for meeting the reasonable requirement of the people for whom they are responsible.<sup>8</sup>

In the absence of this data, we question how ICBs can carry out this legal duty.

Among the ICBs that were able to tell us about the number of children accessing hospice care, the responses varied widely. Whilst Bath and North East Somerset ICB reported a figure of 11 children, Suffolk and North East Essex ICB reported that 1,616 children and young people had accessed hospice care in 2023/24.<sup>vii</sup>

Unfortunately, this lack of local data held by ICBs appears to be a continuing trend. In 2023, we found that only 13 ICBs (31%) were able to tell us 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.<sup>9</sup>

<sup>vii</sup> Note: With regards to the number of children accessing hospice care in 2023/24, North East London ICB have only been able to provide a figure for the number of children accessing Richard House Children's Hospice for quarters one, two and three. This response therefore may not be entirely representative of the whole area.

## Local authority funding

As part of our survey, we also asked children's hospices about the funding they received from local authorities – 32 children's hospice organisations in England provided us with this information.

Under the Children Act 1989, local authorities are required to provide services designed to assist family carers of disabled children 'to continue to provide care, or to do so more effectively, by giving them breaks from caring'.<sup>10</sup>

Despite this legal basis, we have found that the average amount children's hospices receive from local authorities has decreased by 26.1% over the past year. Whilst in 2022/23, on average, children's hospices received £149,939.92 from local authorities representing 3.65% of their charitable expenditure,<sup>11</sup> 2023/24 has seen this funding figure fall to £110,767.56.<sup>viii</sup> Local authority funding now represents approximately 2.64% of children's hospices' charitable expenditure.

We have also found huge variance in local authority funding between children's hospices in England. Over a half (53%) of the children's hospices that responded did not receive any funding from their local authority during 2023/24. Among the remaining hospices that did receive funding, this funding varied from £6,000 to £1,105,000.

**“Local authority funding for hospices remains very low.”**

**Acorns Children's Hospice**

Children's hospice funding from local authorities was also found to vary in terms of the proportions of the charitable expenditure that it represents:

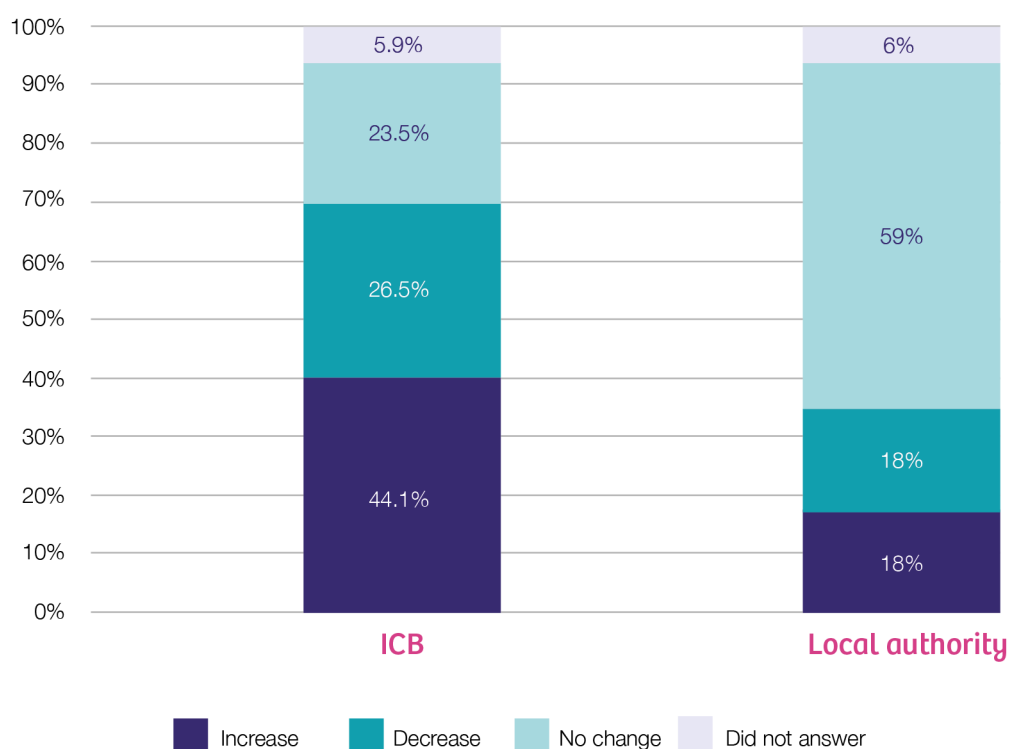
- Nine out of ten (91%) of children's hospices received less than 10% of their charitable expenditure from local authorities.
- Over three quarters (78%) of children's hospices received less than five percent of their charitable expenditure from local authorities.
- Only one children's hospice received more than 30% of their charitable expenditure from local authorities.

When compared to 2022/23, we have found that the number of children's hospices receiving less than 10% of their charitable expenditure from local authorities has increased whilst the number of hospices receiving 30% or more of their charitable expenditure from local authorities has decreased.

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<sup>viii</sup> Please see appendix C for a graph illustrating the change in mean local authority funding for children's hospices across England.

## How do you expect your level of funding from statutory sources for 2024/25 to change, compared to 2023/24



Given that local authorities are legally required to provide short breaks, we are concerned by this variance in local authority funding as well as the fact that 62% of children's hospices reported that their funding either decreased or stood still over the past year.

When asked about their predictions for 2024/25, on average, over a half of children's hospices (59%) expect their ICB funding to remain at current levels. Nearly two fifths (18%) expect it to increase whilst another two fifths (18%) expect it to decrease. Two children's hospices did not answer this question.



## Statutory funding for children's hospices in Northern Ireland

In Northern Ireland, the children's hospice currently receives approximately 30% of its funding from statutory sources.

Whilst we understand from our survey that statutory funding for the Northern Ireland Children's Hospice has increased to £1,971,999 in 2023/24, this increase has not been in line with the rising costs caused by inflationary pressures. As such, the children's hospice continues to be confronted with numerous challenges.

### **"Statutory funding increased but lower than inflationary pressures"**

#### **Northern Ireland Children's Hospice**

In February 2024 the children's hospice announced that, as a result of the loss of government funding for one of its beds, it now intends to run six beds Monday to Friday and three beds Saturday and Sunday. This represents a reduction from the existing seven-beds, seven-nights model.<sup>12</sup>

Following the announcement, Robin Swann MLA, the Northern Ireland Health Minister, asked Department of Health officials to investigate these issues further. He then published a statement setting out the following:<sup>13</sup>

His belief that the financial pressures facing NI Children's Hospice (NICH) go much deeper than any reduction of departmental support.

The reduction in departmental funding involved the ending (in the summer of 2023) of an additional but temporary annual payment of £170,000.

This decision was notified to the NICH in June 2023 and took effect from September 2023 - resulting in an £85,000 reduction in the (2023/24) financial year.

The minister stated that he decided to reinstate this £85,000 funding for 2023/24. This payment would be in addition to the core annual funding of £1.6m which the department was providing directly to NICH in 2023/24.

This core funding included a £420,000 component which had not been recurrent, meaning it would have to be subject to confirmation each year. He confirmed that, going forward, this would be made recurrent, giving the hospice greater certainty.

The children's hospice advised the department that the restoration of the full £170,000 for 2023/24 would not lead to the decision to reduce services being reversed. The minister recognised that Northern Ireland Hospice would need to develop longer-term solutions, to which the minister said the government would want to be supportive.

## Statutory funding for children's hospices in Scotland

Scotland has a national model with Children's Hospices Across Scotland (CHAS) as the single national provider of hospice care to children, with staff working across hospices, hospitals, and local communities. CHAS supports children and their families with medical, nursing, social work, and emotional and family support.

Thanks to support from the Scottish Government and the Convention of Scottish Local Authorities (COSLA), and the generosity of the Scottish public, CHAS provides all care without charge.

However, the numbers of children in Scotland with palliative care needs is going up, and currently CHAS is not reaching every child and family that could benefit from the services it offers.

The Scottish Government has committed that it “will ensure provision of high-quality child palliative care, regardless of location, supported by sustainable funding of at least £7 million per year through Children's Hospices Across Scotland.”<sup>14</sup>

While this funding is highly welcome, inflationary costs, and the expansion of services to meet demand (including in hospital), have increased CHAS' cost base. NHS pay awards have further added to the pressure on CHAS's finances. As a result, the £7 million of annual funding previously awarded by the Scottish Government now only amounts to approximately 30% of CHAS' total expenditure – a shortfall of £3 million per year.

CHAS is urgently calling for a re-commitment to 50% of agreed costs, inclusive of inflation-based uplifts, in order for the Scottish Government to meet its commitment to a long-term sustainable funding arrangement.

This would represent a good investment. The care CHAS provides can stop children from going into hospital, allow earlier discharge, alleviate pressure on the most expensive NHS beds, and stop families from going into crisis. All of which has powerful preventative spend implications.

For every £1 of statutory funding CHAS receives from the Scottish Government and the Convention of Scottish Local Authorities (COSLA), CHAS generates £6.24 of public value in return.<sup>15</sup>

## Statutory funding for children's hospices in Wales

In Wales, the two children's hospices currently receive around 12% of the costs of providing palliative care to children and families from statutory sources. Approximately 67% of this statutory funding is derived from the Welsh Government with the remaining 33% coming from local health boards.

In 2022, as part of the Lifeline Fund, the Welsh Government committed to providing an extra £2.2 million to hospices in Wales with £888,000 going to the two children's hospices, Tŷ Hafan and Tŷ Gobaith.<sup>16</sup>

This was the first time additional statutory funding had been made available to Wales's two children's hospices since 2007 and consequently meant that hospices would receive around 21% of the costs of providing palliative care to children and families in Wales.

At the time, providing this additional statutory funding represented an important step in building towards a sustainable future for the two hospices, allowing them to:

- Recruit more nurses and to build more resilience into their services in the hospices and in the community.
- Extend the breadth and depth of their services and to provide more respite care for those families who so desperately need it.
- Reduce the burden of unplanned and crisis admissions on the NHS.

Despite this previous commitment, inflationary pressures, including difficulties in recruiting and retaining staff stemming from the need to match increased Agenda for Change pay settlements has seen funding challenges exacerbate. As a result, the previous funding that was awarded no longer represents 21% of the hospices' care costs and as such is no longer sustainable.

More recently, at the end of the 2023/24 financial year, an additional £770,000 was awarded to the two children's hospices as part of the Welsh Government's end of life care review.<sup>17</sup>

Whilst this additional funding was very welcome and took the hospices closer to having 21% of care costs for 2023/24 covered by statutory funding (with an average of 20% across the hospices), the payment was non-recurrent and came right at the end of the financial year.

As such, it is by no means a substitute for the long-term sustainable funding that is needed to allow the hospices to plan longer term and reach many more children.

**"The additional funding that was received from Welsh Government in March 2024 for increased cost of living was welcomed, however, it was a one-off payment and had we known of this additional funding sooner it may have impacted the services we provided during the year."**

**Tŷ Hafan Children's Hospice**



## Eve's story

Eve Anderson was a kind and bubbly girl known for her determination, as dad, Ian, explained: “She was vibrant, outgoing and had a real fighting spirit. If someone could do something Eve couldn’t, she’d make it her mission to do it. She’d often come home from school and tell me about the challenge she’d overcome that day.”

This fighting spirit would come to the fore in February 2011 when Eve collapsed in the driveway of her home due to a catastrophic cerebral bleed.

The eight-year-old was admitted to hospital on Valentine’s Day and underwent an 18-hour operation.

A day later, on Tuesday, Eve was in intensive care when surgeons gave her just days to live. Heart-breaking discussions were made as to whether Eve’s life support machine should be switched off on the Thursday.

But the battling eight-year-old defied the odds and woke from her coma three weeks later.

Eve made progress with daily speech and language, and physiotherapy sessions. But worse news was to come when it was discovered that the cerebral bleed was the result of an underlying vascular tumour. This diagnosis wasn’t made in July 2011 when the bleed in Eve’s ventricles finally cleared.

Sadly, Eve suffered a stroke from biopsy surgery and the degenerative damage from intensive daily radiotherapy left her unable to walk or talk.

Eve’s condition was effectively “locked in syndrome” and she used ‘laser eye gaze’ technology to communicate with blinks.

Despite her severe disabilities, Eve’s vibrant sense of humour remained, as dad, Ian, explained: “There was always a glint in Eve’s eye and a big beaming smile on her face.”

Ian – who was to become Eve’s full-time carer – was desperate for his daughter to come home but her complex medical needs meant the home needed extensive adaptations. While these were underway, a social worker suggested St Oswald’s Hospice might be able to help.



Eve initially came to the Hospice three times a week to bathe in the accessible bathroom in the Children and Young Adults Service. Once the adaptations at Ian's home were finished, Eve then started coming to the Hospice for regular short breaks, three days a month.

These short breaks gave Ian a break, while his daughter was cared for in a safe and secure environment. Eve had hydrotherapy and participated in various activities – including a memorable visit to the beach where she rode in a specially adapted horse and carriage.

Ian said: “St Oswald's Hospice became a big part of the family. Coming into the children's unit, it was calm and serene. It wasn't sad or depressing. Everyone was so friendly and wanted to know how you were doing. They are 100% there for the kids and Eve loved her visits.”

Eve had always loved music and after she became ill, her dad would regularly take her to see live music where she “lit up” listening to the musicians play. Such trips, however, ended abruptly when COVID hit and live venues were forced to close.

During this time, Ian reconnected with a friend from Australia, Rob, who had started streaming a music and chat show from his studio, which quickly became a mainstay in the Anderson household – with Eve becoming the show's unofficial mascot.

Ian added: “We would stream the shows on our television and Rob would always give a shout-out to Eve. She loved it!”

Ian had always known the high probability that Eve's brain tumour would one day start growing again and, two years ago, a routine MRI scan revealed his worst fear. Despite the devastating news, Ian continued to make the most of every day with his daughter, who continued to inspire him.

He said: “There were days I was really down but I would go and see Eve. She would sense I was there and flash her sparkling white teeth at me. She motivated me and kept me going.

“Even if I won the world's super lottery, it would never be enough to say thank you and to repay St Oswald's Hospice for giving my daughter her dignity and quality of life back.”

Sadly, Eve's condition began deteriorating. The 20-year-old continued to visit St Oswald's Hospice for short breaks, where she was closely monitored by the team who had known and cared for Eve for the last 12 years.

Eve was on one of her short breaks when the care team became concerned about her and called Ian, who rushed to be with his daughter. After a few days, Eve sadly died at the Hospice on 29 August 2023.

Ian bravely added: “Eve passed away in my arms after blinking three times – her way of saying ‘I love you’.”

“There was something about Eve that left a mark on everyone. No matter how cruel life can be, she was still the most beautiful girl. I feel so proud to have been Eve's dad.”



# Income and expenditure of children's hospices across the UK

In addition to gathering insight into the statutory funding of children's hospices, our survey also sought to examine the current income and expenditure of children's hospices across the UK.

What we have found is very concerning.

## Income

In total, 34 children's hospices across the UK told us about their income.

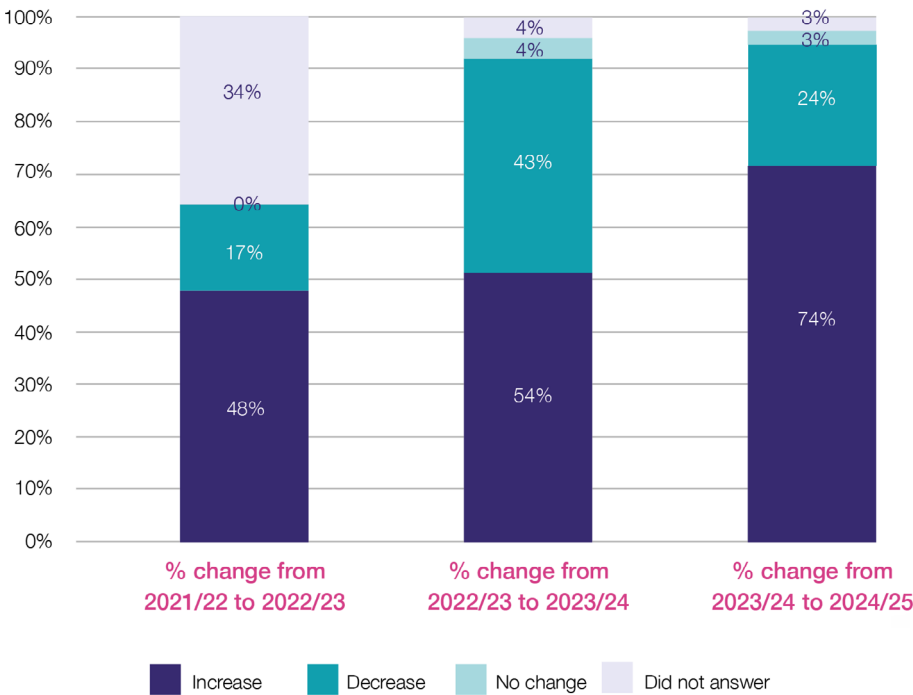
The average income in 2023/24 was £7,313,881. This has decreased slightly compared to the average income of £7,320,470.82 that was received by children's hospices in 2022/23.

In addition to children's hospices' income decreasing over the past year, we have also found income to vary between children's hospices. Over a half (54%) of the children's hospices that responded reported that their income had increased in 2023/24, whilst 13 (47%) children's hospices reported that their income had either decreased or stood still.

Looking ahead to 2024/25, on average, children's hospices across the UK expect their income to increase by six percent to £7,752,006.68.

However, variance is projected to remain between individual children's hospices. Three quarters (74%) of children's hospices expect their income to increase whilst over a quarter (27%) expect their income to either decrease or standstill.

Change in children's hospices income 2020-2025



## Income by source

When examining the individual sources of income, it is clear to see where income has decreased over the past year:

- Income from trading activities has fallen by 14% from £1,987,656.08 in 2022/23 to £1,705,194.52 in 2023/24. This particular income stream now accounts for about 30% of the overall income.
- Legacy income has fallen by 11% from 1,189,330.56 in 2022/23 to £1,054,862.88 in 2023/24. It now accounts for about 13% of the overall income.
- Income from raffles and lotteries has fallen by 19% from £588,756.63 in 2022/23 to £476,807.59 in 2023/24. This income stream now accounts for approximately eight percent of children's hospices' overall income.
- Income from trusts and grants has fallen by 40% from £691,788.81 in 2022/2023 to £414,511.53 in 2023/24, and now accounts for approximately eight percent of the overall income.

Looking ahead to 2024/25, whilst children's hospices predict that legacy income will continue to drop, they predict that income from individual donations, charitable activities and trusts and grants will start to increase.<sup>ix</sup>

## Charitable expenditure

Overall, 36 children's hospice organisations across the UK told us about their charitable expenditure.

On average, children's hospices reported that their charitable expenditure grew by 12% from £4,109,245 in 2022/23 to £4,608,856.08 in 2023/24.<sup>x</sup> When compared to 2021/22, children's hospices' charitable expenditure in England has increased by 15% from an average of £3,633,197.



In terms of the reasons why charitable expenditure has increased over the past year, two thirds (66.7%) of children's hospices attributed the rises in their charitable expenditure to higher energy prices and higher costs of consumables, whilst over a half (63.9%) of hospices claimed the higher expenditure was due to an increase in activity.

In addition to the above, the majority of children's hospices (86.1%) attributed their increased charitable expenditure to higher costs of recruiting and retaining staff.

<sup>ix</sup> Please see appendix E for a graph illustrating the change in children's hospices' average income by source from 2021/22 to 2024/25.

<sup>x</sup> Note: average charitable and total expenditure for 2022/23 was calculated solely using data from children's hospice organisations based in England.

Given the recent increased pay settlements in Agenda for Change roles, the cost of paying hospice staff is rapidly increasing. Hospices recruit from the same pool of staff as the rest of the NHS. There is therefore a need to try to match NHS salaries. However, when NHS wages go up, hospices have to find the funds from their local community in order to match these costs.

**“The largest driver of the increase in our costs is salaries. It is essential that we at least meet the NHS agenda for change salaries in order to be able to recruit and retain care staff.”**

**Claire House Children’s Hospice**

Children’s hospices are committed to paying what they can to staff to try and keep pace with what they would receive if they worked in the NHS. However, in the absence of any improved support from government, many are falling short of matching Agenda for Change.

**“Inflation has had a massive impact on costs, particularly wages from cost of living pressures and having to match NHS pay awards, general pay increases and increases to the National Minimum Wage.”**

**Keech Hospice Care**

These struggles are further compounded by the high vacancy rates in the clinical workforce of children’s hospices across the UK. According to a recent survey of the hospice workforce conducted by Hospice UK, there is currently an average vacancy rate of 14.5% in the clinical workforce among children’s hospices.<sup>18</sup>

Nearly one in four (24%) posts for newly registered nurses or nurse practitioners within two years of qualification are vacant. One in five (20%) of healthcare assistant and support worker posts are vacant. 17% of other non-senior registered nursing posts are vacant.

These rates are higher than in the NHS in England, which had a vacancy rate of 10.3% as of 30 September 2023 within the Registered Nursing staff group.<sup>19</sup>

The increased charitable expenditure also demonstrates the impact of rising energy costs.

Children’s hospices use huge amounts of energy to care for children at the end of their lives.

Even with the Energy Bills Discount Scheme that businesses struggling with rising energy prices have been able to benefit from over the past year, two thirds of children’s hospices have attributed their increased charitable expenditure to higher energy prices.

The Energy Bills Discount Scheme came to an end on 31 March 2024. In the absence of long-term sustainable funding, hospices will need more generous support so that the cost of living crisis - or other future crises - doesn’t affect the care children receive at the end of their life.

This is particularly important given that children’s hospices expect their charitable expenditure to continue increasing. In 2024/25, they have predicted it will increase by 15% to £5,278,183.14.

## Total expenditure

When asked about their total expenditure, 33 children's hospices across the UK provided us with information.<sup>xi</sup>

On the whole, children's hospices' total expenditure, which includes fundraising costs, rose on average by 11% from £7,238,435.54 in 2022/23 to £8,056,629.06 in 2023/24.

Children's hospices expect this trend to continue in 2024/25 and have predicted that their total expenditure will rise again by 13% to £9,064,763.42.



## Balance between total income and total expenditure

As part of our analysis, we subtracted individual children's hospices total expenditure from the total income they reported receiving in 2023/24 to understand the extent to which children's hospices were experiencing a surplus or deficit.

Only a quarter of children's hospices (26%) across the UK reported a net surplus or breaking even in 2023/24. This is a significant decrease on the 57% of children's hospices that reported a surplus in 2022/23.

On the other end of the spectrum, over a half (54%) of children's hospices reported a net deficit. This is an increase on the 43% of children's hospices that reported a deficit in 2022/23. Eight hospices either did not provide a response or their response was omitted due to factoring in costs for adult services in addition to children's services.

When taking all respondents' surpluses and deficits into account, on average, children's hospices across the UK reported a deficit of £218,491.84 in 2023/24. When extrapolated across all 39 children's hospice organisations in the UK, this would represent a shortfall of £8,521,182.

<sup>xi</sup> Note: Due to providing services for adults as well as children, some hospices were not able to separate their total expenditure for children and adults' services. To ensure our analysis was representative of children's hospice services alone, data covering both adult and children's services was omitted from the analysis.



**“Costs have increased due to inflation in almost every area. In particular staff costs, which represent a significant proportion of Demelza’s expenditure, have increased due to 5-8% salary increases to ensure staff continue to receive the Real Living Wage. Whilst costs have increased by 12%, income has increased by less than this (9.7%) creating a real-term reduction.”**

**Demelza**

Looking ahead to 2024/25, the picture gets even worse.

Nearly three quarters (72%) of children’s hospices have forecast a net deficit, whilst eight percent expect to make a surplus. Eight children’s hospices did not provide a response.

On average, children’s hospices expect to report a deficit of £772,489.61. When extrapolated across all 39 children’s hospice organisations in the UK, this would represent a shortfall of £30,127,094.90 in 2024/25.

### **Impact of funding changes on services**

In our survey, we also asked children’s hospices about the impact funding changes have had on the care and support they provide - 37 children’s hospices told us about the impact they have seen.

Across the range of types of care and support, a majority of children’s hospices are either expanding or maintaining them at current levels.

It is encouraging to see that 86% of children’s hospices have either expanded or maintained the end of life care they provide in 2023/24 compared to 2022/23, whilst 67% have expanded or maintained their respite provision.

Similarly, 86% have expanded or maintained services related to symptom management.

Despite these encouraging trends, we are concerned to hear that many children’s hospices have reported using their reserves or relying more on charitable income in order to maintain services at current levels.

**“We have used our reserves to ensure no impact but have not been able to expand as much as we would have liked, and this is not sustainable in the long term.”**

**Alexander Devine Children’s Hospice Service**

**“The end users of our services have not been impacted as we have used reserves to ensure the level of service they receive is unaffected.”**

**Helen and Douglas House**

**“Our direct funding has decreased in real terms, so we have used a higher proportion of charitable funding in the service.”**

**St Oswald’s Hospice**

We are also concerned that 30% of children's hospices have had to cut respite care or short breaks. Meanwhile, eight percent have had to cut or stop providing end of life care.<sup>xii</sup>

**"Families can no longer easily access inpatient care – either for end of life or for respite purposes."**

### **St Andrew's Hospice/Andy's Children's Services**

#### **Active caseloads**

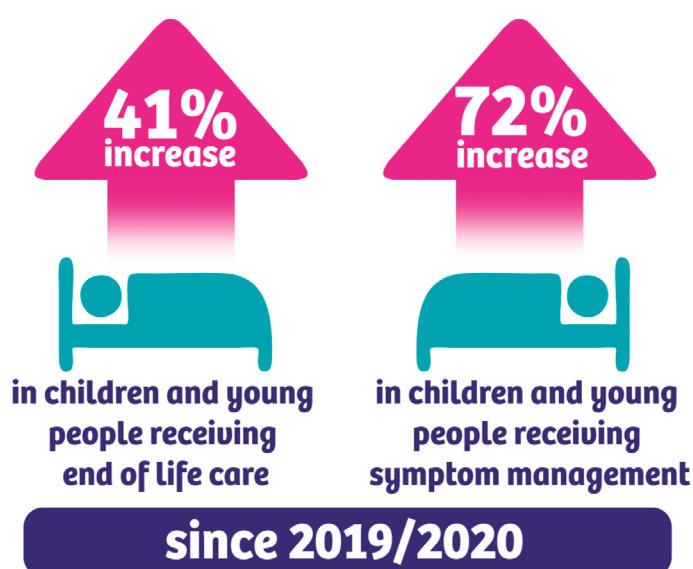
We have found that, on average, children's hospices' active caseload has decreased by 9% from an average of 272 in 2022/23 to 248 in 2023/24.

Of the care that should be funded by the NHS, children's hospices reported the following:

- Respite care and short breaks were provided to 15% more children and young people increasing from 134 in 2022/23 to 154 in 2023/24.
- Symptom management was provided to 17% more children and young people increasing from 56 in 2022/23 to 65 in 2023/24.
- End of life care was provided to 14% fewer children and young people decreasing from 21 in 2022/23 to 18 in 2023/24.
- Hospice at home was provided to 16% fewer children and young people decreasing from 110 in 2022/23 to 92 in 2023/24.
- Step down care was provided to 14% fewer children and young people decreasing from five in 2022/23 to four in 2023/24.

When examining the trends witnessed over the past five years since 2019/20, it is evident that children's hospices are providing significantly more of the care that the NHS should be funding. Over the years, end of life care and symptom management has been provided to two fifths (41%) and three quarters (72%) more children and young people respectively. Similarly, step down care has been provided to two fifths (41%) more children and young people.<sup>xiii</sup>

Not only is this symptomatic of the increasing prevalence in the numbers of children with life-limiting or life-threatening conditions, but it also shows the pressure that children's hospices relieve off the NHS and local health and social care systems.



<sup>xii</sup> Please see appendix F for a graph illustrating impact that changes in funding between 2022/23 and 2023/24 have had on the services provided by children's hospices.

<sup>xiii</sup> Please see appendix G for a graph illustrating the change in average caseloads from 2019/20 to 2023/24.



## Albie and Louis' story

Albie and Louis are twin boys aged two. Their family are supported by Jessie May nurses.

Their specialist nurses provide at home nursing and respite care for children and young people that have a terminal or life-limiting condition throughout the South West.

“Our Lifetime nurse could see that we were exhausted and struggling with caring for the boys. She referred us to Jessie May with a view to getting us some help,” said their mum, Alex.

Alex was nervous about welcoming new people into her home: “It’s very unnerving to go from living a ‘normal’ life, to suddenly having lots of professionals involved and people in your home environment. However, the team were so friendly and were amazing with the boys, I felt at ease very quickly.”

### Helping with the day to day

The Jessie May team play with the boys, feed them, bath them and get them ready for bed: “These are some of the most stressful components of their routine.”

This support frees up Alex to spend some one-to-one time with her eldest son: “I can pick him up from school by myself and we will often do an activity together.”

“When you see people making your child feel special and loved, it’s different to other care providers. The team always seem excited to see the boys, which is so reassuring.”

Caring for children with complex needs like Albie and Louis can be challenging and stressful, so the support of nurses from Jessie May is so important to families like theirs: “Caring for any child is not all smiles and giggles, especially children with complex needs. The team take the tantrums, the flying food and medical needs all in their stride, nothing phases them!”

### They just understand

When asked what it means to the family, Alex shared: “Charities often have a focus on the children that are unwell or have additional needs. Behind all of those children is a family that are exhausted and continually fighting for support. Jessie May understands that caregivers need some respite. To have a team that strives to make life easier for you, in what can be a very isolated place, is just incredible. Thank you Jessie May.”

## Policy recommendations

Across the UK, we are witnessing children's hospices be financially stretched despite the lifeline care they provide to seriously ill children. We therefore recommend the following action to make sure that children's hospice care across the UK is sustainable for the long-term.

### England

1. Review the way in which children's hospice care is funded to ensure children's hospices are equipped to provide lifeline care and support to seriously ill children and their families for the long-term.
2. Commit to maintaining, ringfencing and increasing the £25 million NHS England funding for children's hospices by the rate of inflation – and returning it to being a centrally-distributed funding stream.
3. Hold ICBs to greater account for the way in which they commission children's palliative care.
4. Direct ICBs to work with neighbouring ICBs in their region to plan and fund key services.
5. Ensure local authorities have the funding they need to comply with their legal duty to provide short breaks to families of seriously ill children.

### Northern Ireland

1. Commit to providing additional and sustainable statutory funding to Northern Ireland Children's Hospice for the long-term. This funding should be sufficient to cover 50% of the costs incurred in providing lifeline care and support to children and their families.
2. Ensure that any additional and recurrent statutory funding that is awarded is tied to and increases in line with the rising costs caused by inflationary pressures.

### Scotland

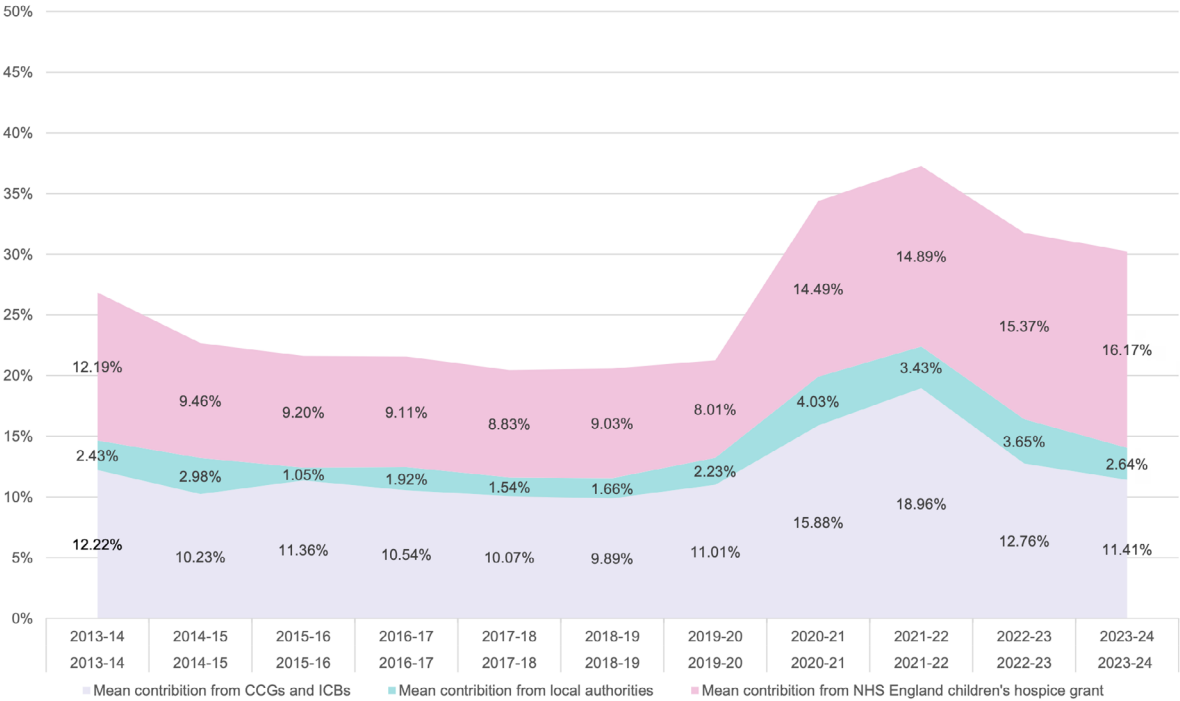
1. Re-commit to providing additional and sustainable statutory funding to Children's Hospices Across Scotland (CHAS) for the long-term. This funding should be sufficient to cover 50% of agreed costs in providing lifeline care and support to children and their families.
2. Ensure that any additional and recurrent statutory funding that is awarded is tied to and increases in line with the rising costs caused by inflationary pressures.

### Wales

1. Commit to providing long-term, sustainable and fair funding to Tŷ Hafan and Tŷ Gobaith. This funding should be sufficient to cover at least 21% of the costs incurred in providing lifeline care and support to children and their families.
2. Ensure that any additional and recurrent statutory funding that is awarded is tied to and increases in line with the rising costs caused by inflationary pressures.

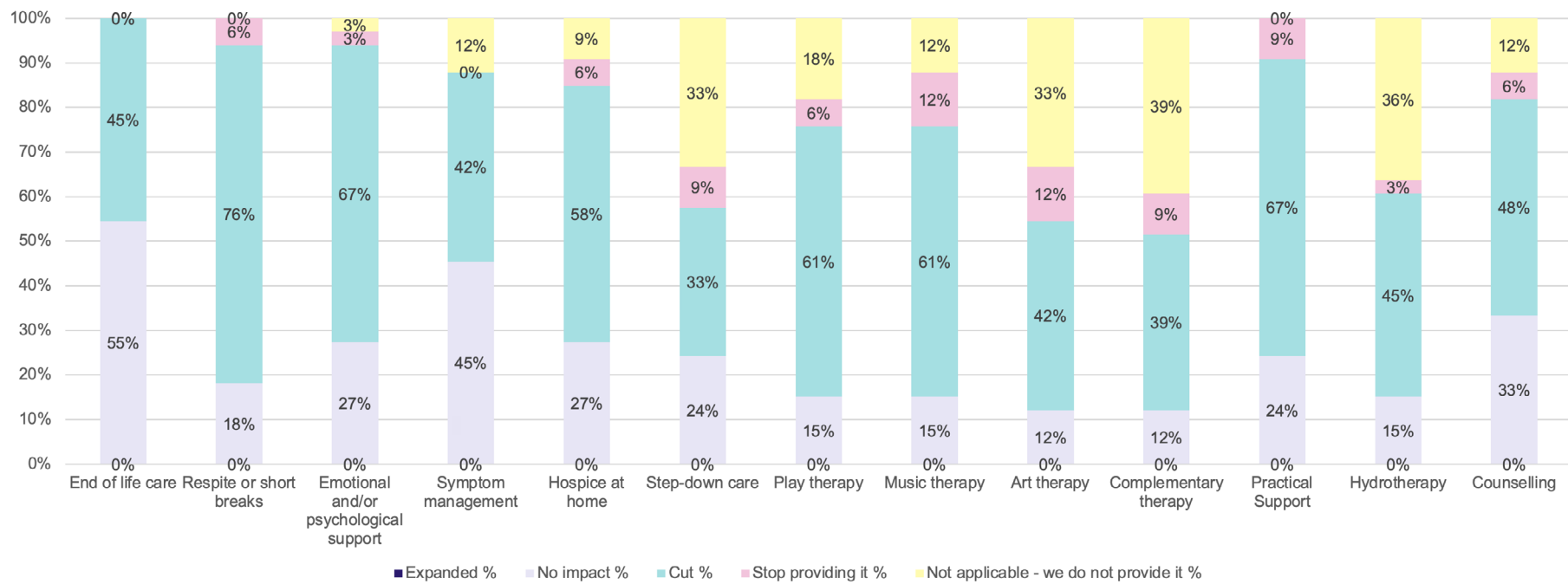
# Appendices

Appendix A: Proportion of the charitable expenditure for children’s hospices in England covered by the state 2014-24





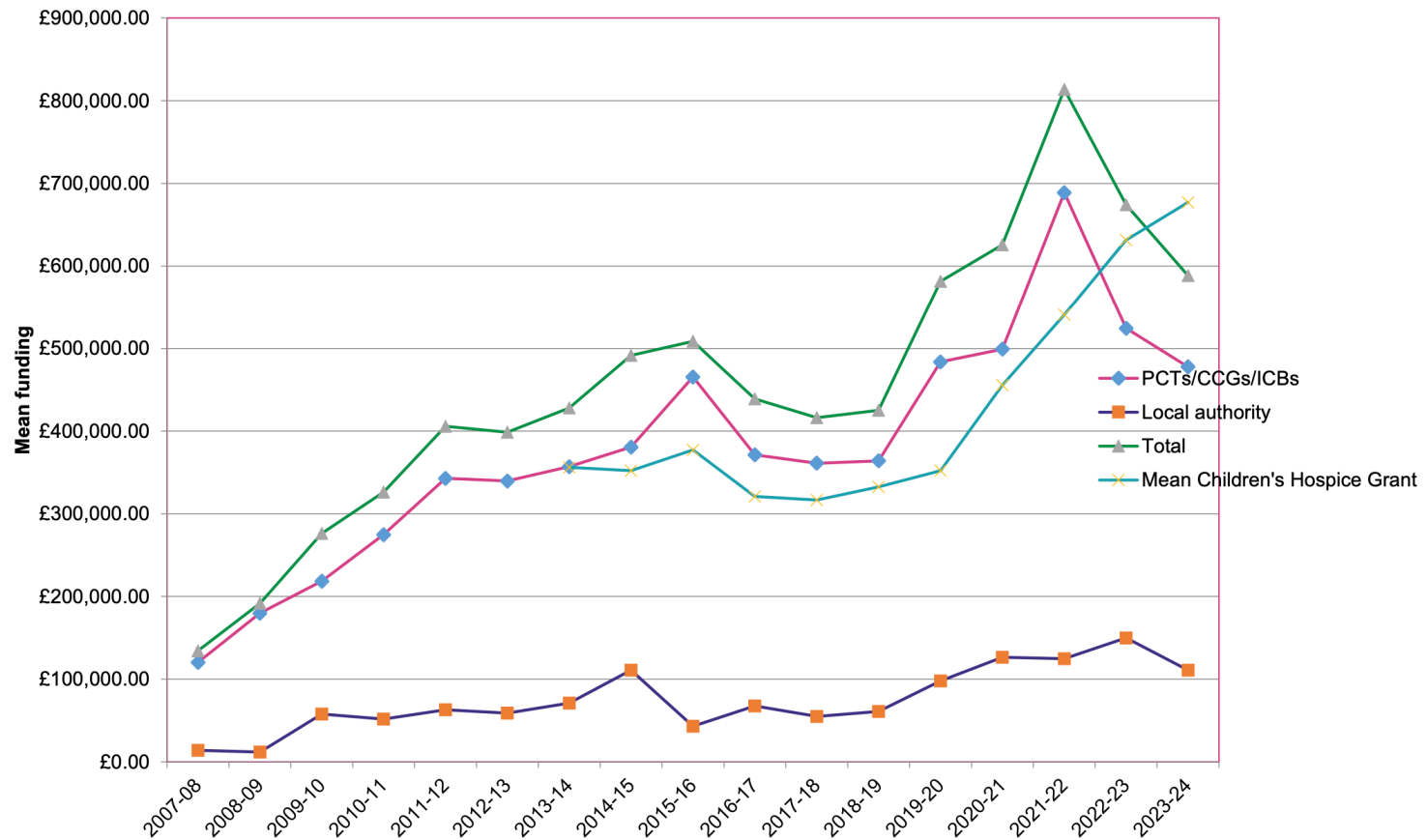
## Appendix B: The predicted impact on children's hospice services if NHSE funding for children's hospices was not available from 2025/26 onwards



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Children's hospice funding in 2024

## Appendix C: Change in mean local funding for children's hospices in England 2007-24



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Children's hospice funding in 2024

## Appendix D: Overview of responses from ICBs to our freedom of information requests

Integrated care board	2023/24 total spending by ICB on children's hospice care	Total number of children and young people aged 0-18 accessing hospice care in ICB footprint	2024/25 total spending by ICB on children's hospice care	Number of cases of life-limiting and life-threatening conditions (LLCs and LTCs) among children and young people aged 0-24 in ICB area	2023/24 total spending by ICB on children's hospice care per number of cases of life-limiting and life-threatening conditions (LLCs and LTCs) among children and young people aged 0-24 in each ICB area (£ per child and young person)
Bath and North East Somerset, Swindon and Wiltshire	£245,200.00	11	£178,609.00	1,456	£168.41
Bedfordshire, Luton and Milton Keynes	£173,000.00		£173,000.00	2,101	£82.34
Birmingham and Solihull	£746,172.00			2,871	£259.90
Black Country	£461,916.55	210		3,104	£148.81
Bristol, North Somerset and South Gloucestershire	£738,047.28			1,859	£397.01
Buckinghamshire, Oxfordshire and Berkshire West				2,945	
Cambridgeshire and Peterborough	£398,058.00	198	£402,007.56	1,540	
Cheshire and Merseyside	£1,004,439.00			4,856	£206.84
Cornwall and Isles of Scilly	£117,000.00	109	£118,000.00	1,076	£108.74

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Children's hospice funding in 2024

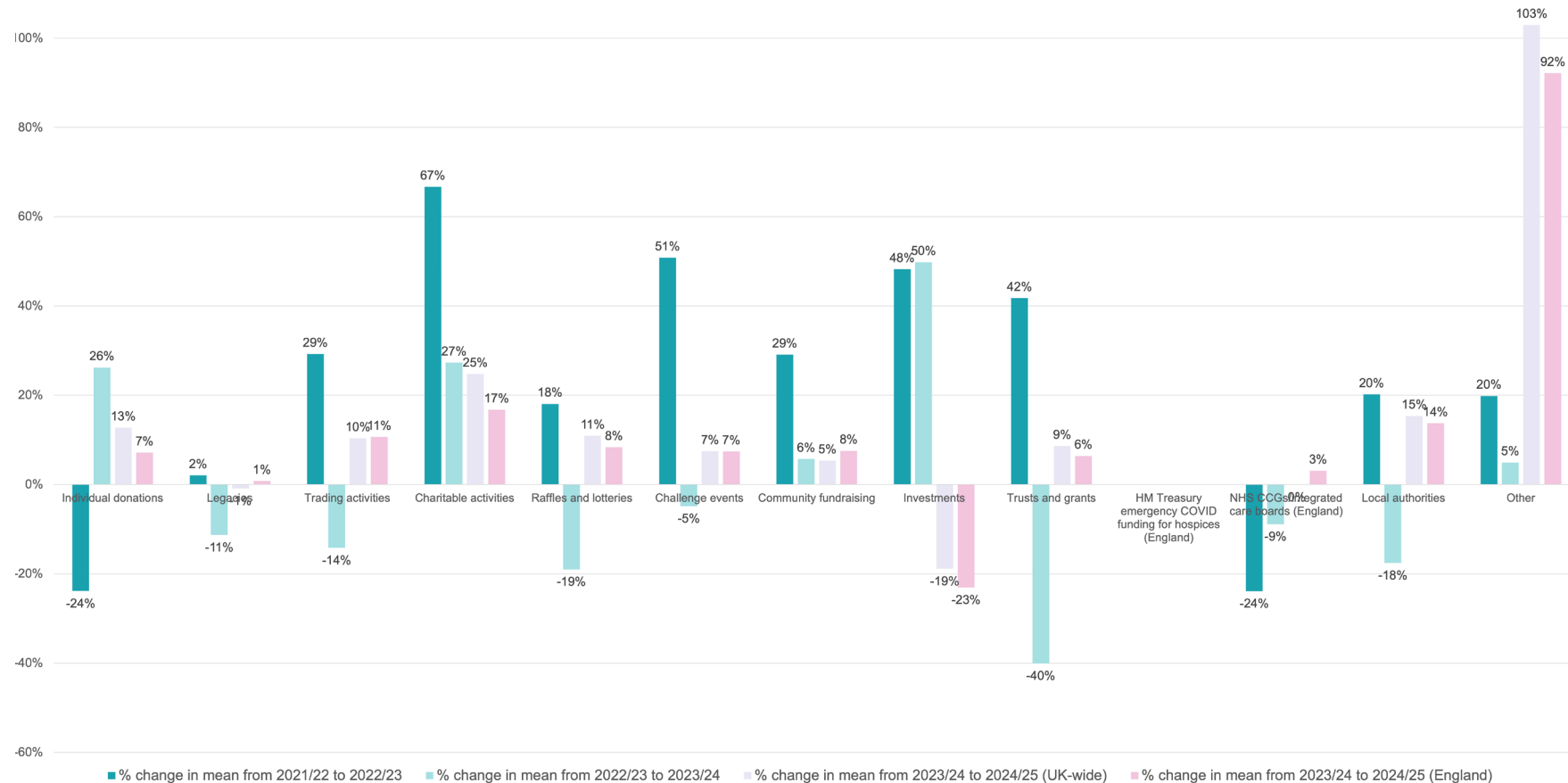
Integrated care board	2023/24 total spending by ICB on children's hospice care	Total number of children and young people aged 0-18 accessing hospice care in ICB footprint	2024/25 total spending by ICB on children's hospice care	Number of cases of life-limiting and life-threatening conditions (LLCs and LTCs) among children and young people aged 0-24 in ICB area	2023/24 total spending by ICB on children's hospice care per number of cases of life-limiting and life-threatening conditions (LLCs and LTCs) among children and young people aged 0-24 in each ICB area (£ per child and young person)
Coventry and Warwickshire	£235,950.00	163		1,596	£147.84
Derbyshire	£126,700.00	46	£126,700.00	1,746	£72.57
Devon	£298,902.00		£298,902.00	2,075	£144.05
Dorset	£122,416.37	31		1,251	£97.85
Frimley	£246,000.00		£247,000.00	1,297	£189.67
Gloucestershire	£252,941.25	192	£267,947.00	1,105	£228.91
Greater Manchester	£470,401.00			6,241	£75.37
Hampshire and the Isle of Wight	£49,552.84	36		3,373	
Herefordshire and Worcestershire	£262,610.00	118	£264,185.00	1,257	£208.92
Hertfordshire and West Essex	£674,557.00			2,552	£264.32
Humber and North Yorkshire	£155,373.00		£156,173.00	2,755	£56.40
Kent and Medway	£102,183.00			3,301	£30.96
Lancashire and South Cumbria	£453,891.00		£353,877.00	3,437	£132.06

<b>Integrated care board</b>	<b>2023/24 total spending by ICB on children's hospice care</b>	<b>Total number of children and young people aged 0-18 accessing hospice care in ICB footprint</b>	<b>2024/25 total spending by ICB on children's hospice care</b>	<b>Number of cases of life-limiting and life-threatening conditions (LLCs and LTCs) among children and young people aged 0-24 in ICB area</b>	<b>2023/24 total spending by ICB on children's hospice care per number of cases of life-limiting and life-threatening conditions (LLCs and LTCs) among children and young people aged 0-24 in each ICB area (£ per child and young person)</b>
Leicester, Leicestershire and Rutland	£99,893.00		£99,893.00	1,739	£57.44
Lincolnshire	£62,300.00	93	£62,673.80	1,113	£55.97
Mid and South Essex	£637,147.00	328	£571,147.00	2,079	£306.47
Norfolk and Waveney	£385,222.00	1549	£360,222.00	1,477	£260.81
North Central London	£61,546.95			2,719	
North East and North Cumbria	£120,172.00		£120,893.00	6,019	£19.97
North East London	£1,217,604.00	118		4,006	£303.95
North West London				4,068	
Northamptonshire	£42,000.00	57	£42,000.00	1,373	£30.59
Nottingham and Nottinghamshire	£89,300.00			1,926	£46.37
Shropshire and Telford and Wrekin				881	
Somerset	£170,000.00			1,011	£168.15
South East London	£116,368.28			3,400	£34.23
South West London				2,860	
South Yorkshire	£108,000.00			3,270	£33.03



Integrated care board	2023/24 total spending by ICB on children's hospice care	Total number of children and young people aged 0-18 accessing hospice care in ICB footprint	2024/25 total spending by ICB on children's hospice care	Number of cases of life-limiting and life-threatening conditions (LLCs and LTCs) among children and young people aged 0-24 in ICB area	2023/24 total spending by ICB on children's hospice care per number of cases of life-limiting and life-threatening conditions (LLCs and LTCs) among children and young people aged 0-24 in each ICB area (£ per child and young person)
Staffordshire and Stoke on Trent	£182,615.00		£602,613.00	2,027	£90.09
Suffolk and North East Essex	£342,000.00	1616		1,553	£220.22
Surrey Heartlands	£484,230.00			1,744	£277.65
Sussex	£500,000.00	23	£500,000.00	2,980	£167.79
West Yorkshire	£673,317.00			5,318	£126.61

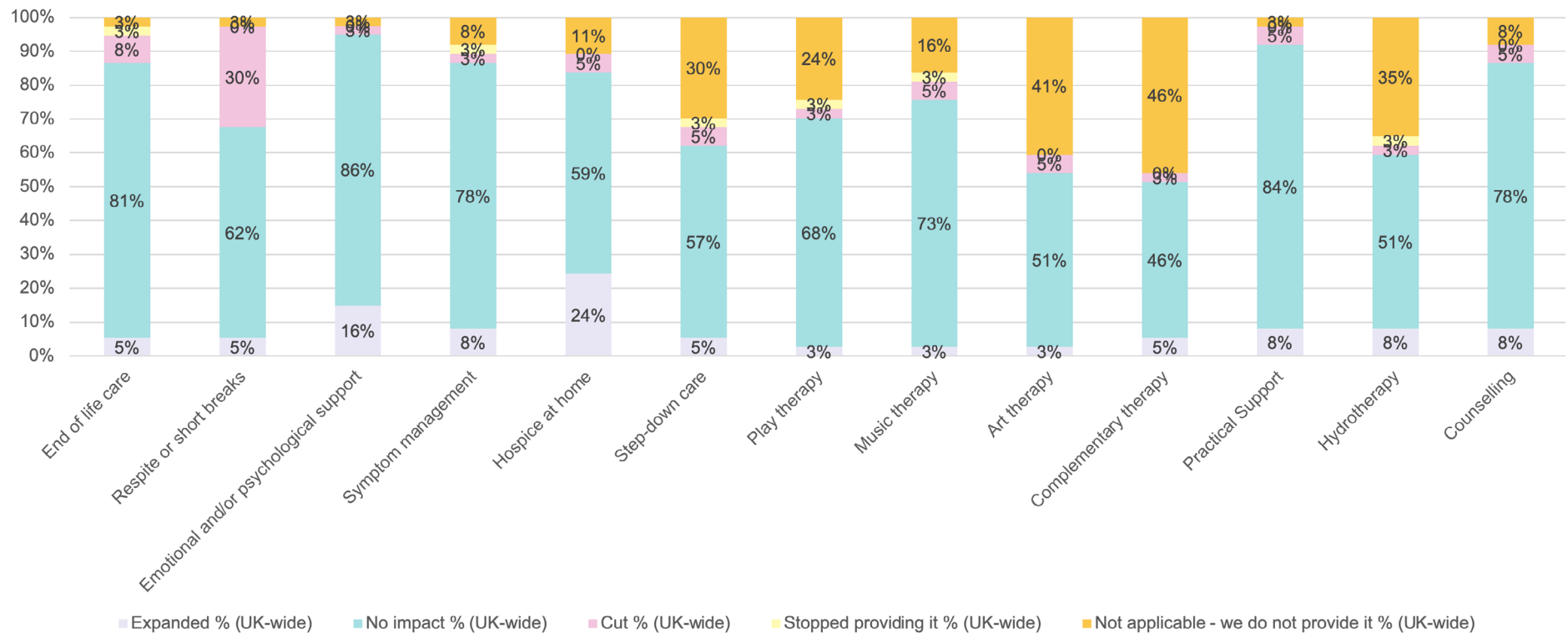
## Appendix E: Change in children's hospices' average income by source from 2021/22 to 2024/25



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Children's hospice funding in 2024

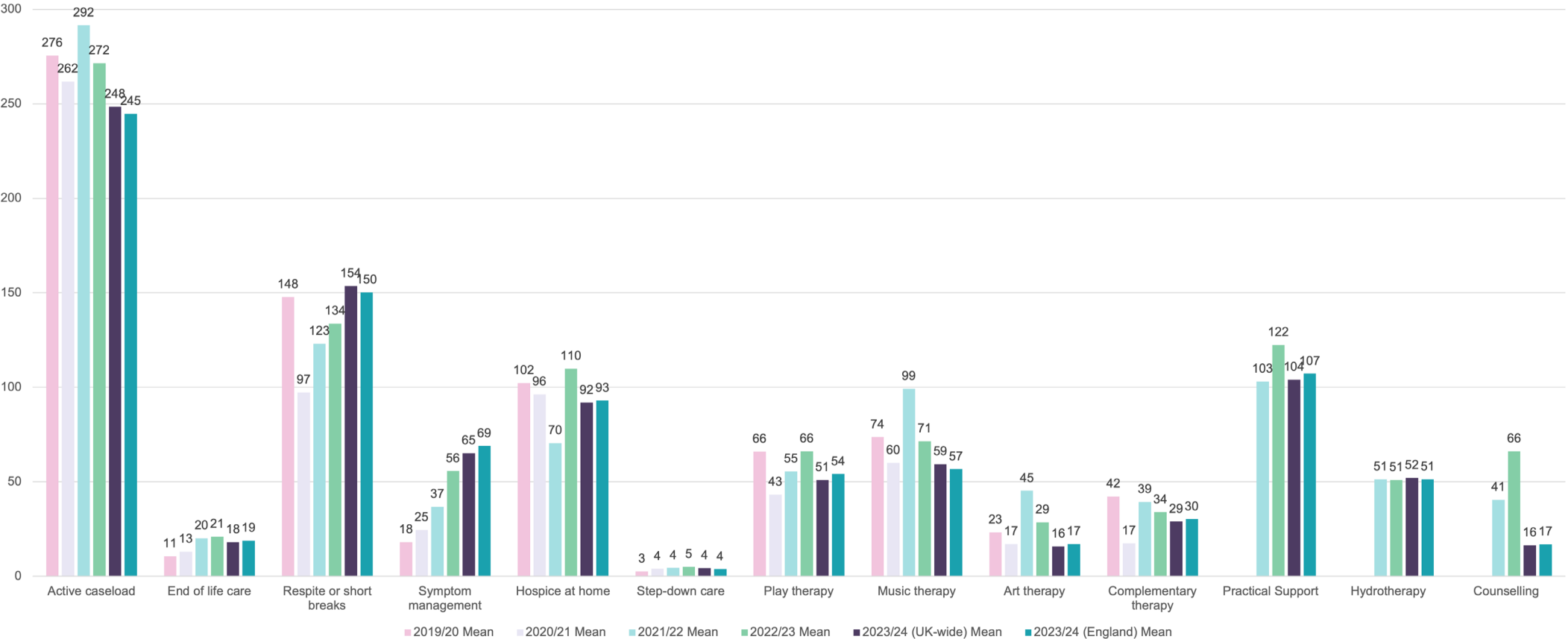
## Appendix F: Impact that changes in funding between 2022/23 and 2023/24 have had on the services provided by children's hospices



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Children's hospice funding in 2024

Appendix G: Change in average caseloads from 2019/20 to 2023/24



Short Lives Can't Wait

Children's hospice funding in 2024

## Appendix H: Responses from ICBs to our freedom of information requests

[Bath and North East Somerset, Swindon and Wiltshire ICB.pdf](#)

[Bedfordshire, Luton and Milton Keynes ICB.pdf](#)

[Birmingham and Solihull ICB.pdf](#)

[Black Country ICB.pdf](#)

[Bristol, North Somerset and South Gloucestershire ICB.pdf](#)

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[Cheshire and Merseyside ICB.pdf](#)

[Cornwall and Isles of Scilly ICB.pdf](#)

[Coventry and Warwickshire ICB.pdf](#)

[Derby and Derbyshire ICB.pdf](#)

[Devon ICB.pdf](#)

[Dorset ICB.pdf](#)

[Frimley ICB.pdf](#)

[Gloucestershire ICB.pdf](#)

[Greater Manchester ICB.pdf](#)

[Hampshire and Isle of Wight ICB.pdf](#)

[Herefordshire and Worcestershire ICB.pdf](#)

[Hertfordshire and West Essex ICB.pdf](#)

[Humber and North Yorkshire ICB.pdf](#)

[Kent and Medway ICB.pdf](#)

[Lancashire and South Cumbria ICB Expenditure.pdf](#)

[Lancashire and South Cumbria ICB.pdf](#)

[Leicester, Leicestershire and Rutland ICB.pdf](#)

[Lincolnshire ICB.pdf](#)

[Mid and South Essex ICB.pdf](#)

[Norfolk and Waveney ICB.pdf](#)

[North Central London ICB.pdf](#)

[North East and North Cumbria ICB.pdf](#)

[North East London ICB.pdf](#)

[North West London ICB.pdf](#)

[Northamptonshire ICB.pdf](#)

[Nottingham and Nottinghamshire ICB.pdf](#)

[Somerset ICB.pdf](#)

[South East London ICB.pdf](#)

[South West London ICB.pdf](#)

[South Yorkshire ICB.pdf](#)

[Staffordshire and Stoke on Trent ICB.pdf](#)

[Suffolk and North East Essex ICB.pdf](#)

[Surrey Heartlands ICB.pdf](#)

[Sussex ICB.pdf](#)

[West Yorkshire ICB.pdf](#)



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