



Children's hospice funding in 2022/23

A REPORT BY TOGETHER FOR SHORT LIVES

Introduction

In April and May 2023, Together for Short Lives asked children's hospices across England how they were funded in 2022/23. We asked what impact this has had on the services they have been able to provide to seriously ill children and their families. We also asked them how they expected this to change in 2023/24.

29 of England's 34 children's hospice organisations responded to our survey. All provide children's hospice and palliative care to children and young people. This report summarises their responses and sets out the action we v on the UK Government and NHS England (NHSE) to take to equitably and sustainably fund children's hospices.

We summarise the funding landscape for children's hospices in other parts of the UK at the end of this report.

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.

We use CCG/ICB in this report 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.

Executive Summary

Children’s hospices across England are providing more and more complex care and support to children and young people with life-limiting or life-threatening conditions, offering a lifeline to their families and taking pressure away from the NHS. Their costs are rising rapidly as inflation and the price of recruiting and retaining skilled and experienced staff soars.

Funding for children’s hospices from local NHS organisations (integrated care boards, or ICBs) is patchy and nowhere near the level that will sustain the crucial hospice services that seriously ill children and families need. Yet NHS England (NHSE) plans to end the crucial £25 million annual Children’s Hospice Grant at the end of this year (2023/24), leading to cuts in vital end of life care, short breaks for respite and services to manage children’s symptoms.

UK Government ministers must urgently protect the £25 million Children’s Hospice Grant, distribute it centrally through NHSE as a ringfenced fund as it is now, and increase it by the rate of inflation beyond 2023/24.

Children’s hospices are essential in local health and care systems across England. In 2022/23, on average they provided more round-the-clock care and support that should be funded by NHS in hospices and in family homes, including:

- services to manage symptoms, including pain, to 51% more children (56 per children’s hospice compared to 37 in 2021/22)

- short breaks for respite to 9% more children and families (134 per children’s hospice compared to 123 in 2021/22)

- end of life care to 4% more children (21 per children’s hospice, compared to 20 in 2021/22)

The charitable expenditure they incurred in doing so (which does not include the costs of their fundraising activities) grew by 13% from £3.61 million in 2021/22 to £4.07 million in 2022/23. Nearly all (93%) of children’s hospices say this resulted from the higher costs of recruiting and retaining staff. Two thirds (66%) attributed them to higher energy prices. Just over half (59%) said costs were higher because they had increased their activity.

On average, income for children’s hospices in England grew by 2% from £7.18 million in 2021/22 to £7.32 million in 2022/23, driven in part by the welcome increase in the NHSE Children’s Hospice Grant over the same period.

The grant is a crucial and welcome contribution to the cost of providing lifeline hospice care to children and families. In 2022/23, when the total grant was worth £21 million, it represented, on average, £1 of every £6.50 (15%) of charitable spending by children’s hospices. NHSE has increased the grant to £25 million in 2023/24, as it committed to do back in 2019.

However, NHSE wrote to children’s hospices in April to tell them that this year (2023/24) will be the final year of the grant – and that ICBs would be responsible for all of their NHS funding thereafter.

Together for Short Lives believes that it is right that ICBs are responsible for understanding the needs of seriously ill children and families within their local populations. They should be responsible for allocating some NHS funding to children's hospices.

However, we are very concerned that ICB funding is patchy and nowhere near the level that will sustain the crucial hospice services that children and families need. Children with life-limiting and life-threatening conditions 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 CCGs and ICBs from the UK Government and NHSE, such as the NHS Long Term Plan children's palliative care match funding, which not all CCGs – or subsequently ICBs – have chosen to access. The non-recurrent £25million funding for children's and adult hospices in 2019/20 announced by the Prime Minister in August 2019 is another case in point.

In 2022/23, children's hospices received an average of £532,923 from NHS clinical commissioning groups and ICBs¹, nearly a quarter (23%) less than the £688,830 they received from CCGs in 2021/22. This represented £1 in every £8 of their charitable expenditure (13%), down from the £1 in every £5 (20%) that CCGs funded in 2021/22.

One in 10 (10%) children's hospices received over 30% of their charitable expenditure from CCGs/ICBs. One in three (34%) received 5% or less of their charitable expenditure from CCGs/ICBs. While models of children's hospice services vary between

providers, this level of variation in funding cannot be justified.

Children's hospices have told us what the impact on their services would be if the Children's Hospice Grant was not available from 2024/25 onwards as a ringfenced grant from NHSE. The results are very worrying:

- Nearly two in five (38%) children's hospices would cut end of life care they provide. One would stop providing it altogether.
- Nearly four fifths (79%) would cut the respite or short breaks they provide. One would stop providing them altogether.
- Two thirds (66%) would cut the hospice at home services they provide. One would stop providing them altogether.

As a result of growing costs, over four-fifths (86%) of children's hospices forecast a net deficit in 2023/24. Just 14% expect to make a surplus. Removing the Children's Hospice Grant in 2024/25 would destabilise children's hospices' finances even further.

We call for the following action to make sure that children's hospice care in England is sustainable for the long-term – and funded on a more equitable basis:

1. Protect, ringfence and increase the NHS England Children's Hospice Grant by the rate of inflation: we call on ministers and officials to maintain the Children's Hospice Grant as a ringfenced, centrally distributed funding stream from NHS England, as is the case now. This will make sure that NHS funding meant for children's hospices reaches children's hospices.
2. Hold integrated boards (ICBs) to account: the Secretary of State for Health and Social

¹ CCGs were abolished and replaced by ICBs in July 2022 as a result of the Health and Care Act 2022.

Care should use their new powers in the Health and Care Act 2022 to direct NHSE to make sure that all seriously ill children in England and their families should be able to choose to receive palliative care from children's hospices, if it is in their best interests. This should build on the legal duty on integrated care boards (ICBs) in the Health and Care Act to commission palliative care as they consider appropriate for meeting the reasonable requirements of the people for whom they are responsible.

3. Local and regional action: ICBs should take our findings into account as they determine the health and healthcare needs of their populations. ICBs should commission children's hospice and palliative care services in a way which is consistent with their legal duty and the policy framework set out by NHS England and the National Institute for Health and Care Excellence (NICE). NHSE should regularly monitor the extent to which ICBs do this through the strategic clinical networks

(SCNs) – and hold them to account if they fail to do so.

4. Government funding for short breaks: HM Treasury should meet the annual £573 million funding gap in social care for disabled children in England identified by the Disabled Children's Partnership; local authorities could use this funding to make sure that short breaks for respite for families of seriously ill children, including those provided by children's hospices, are sustainable for the long-term.

If the UK Government, NHSE and ICBs fail to take this action, 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.

Contents

2	Introduction
3	Executive summary
7	The NHSE/I Children and Young People's Hospice Grant
8	End of life care
10	Short breaks for respite
12	Hospice at home
14	Symptom management
16	Impact on other services
17	Local NHS funding in England
22	Local authority funding in England
22	Qualitative feedback from children's hospices about how they are funded by the state
25	Income
28	Income by source
29	Charitable expenditure
32	Total expenditure
32	Balance between total income and total expenditure
33	Impact of funding changes on services
36	Active caseloads
39	The impact that children's hospices have on their wider local and/or regional health and social care system
43	Policy recommendations
44	Children's hospice funding in Northern Ireland
46	Children's hospice funding in Scotland
48	Children's hospice funding in Wales

The NHSE/I Children and Young People's Hospice Grant

1. In July 2019, NHSE/I decided to increase the Children's Hospice Grant to £25million by 2023/24 and ringfence this money specifically for children's hospices. Through the hospice at home services they provide, often in collaboration with NHS community teams, children's hospices can play an important role in making sure 24/7 palliative care is available to children who need it. The planned Children's Hospice Grant amounts during this period have been:

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

2. This additional NHS funding for children's hospices is very welcome and comes at a time when they are providing care and support to a growing number of seriously ill children and families who have increasingly complex needs. However, NHSE has not committed to maintaining the grant as a protected, ringfenced funding stream for children's hospices beyond 2023/24.

3. Together for Short Lives believes that it is right that ICBs are responsible for understanding the needs of seriously ill children and families within their local populations. They should be responsible for allocating some NHS funding to children's hospices. However, we believe that devolving all NHS children's hospice funding to ICBs could exacerbate the current 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.

4. The non-recurrent £25million 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.

5. Together for Short Lives surveyed children's hospices in England in September 2020 to understand the extent to which they had been able to access this funding. Fifteen (44%) organisations in England responded out of a total of 34. 11 respondents only provided hospice care to children and young people. Four of the organisations provided hospice care to people of all ages.

6. The average funding received by 11 respondents that only provided hospice care to children & young people was £134,593 per organisation. Ten of the eleven received funding. The average funding received per CCG was £29,137. However, individual CCG sums for the children's hospices ranged widely from £1,425 to £100,000.

7. Children's hospices gave us this feedback on the process of applying for the money:

- “The process was not very clear and each CCG seemed to interpret the guidance in a different way.”
- “Some CCGs wanted specific project bids whilst others allocated purely towards hospice running costs.”
- “The process was extremely varied depending on the CCG we were engaging with or trying to engage with in some cases. Some were proactive and even met us in person to discuss the opportunity and how the allocation process would work. Others simply refused to speak to us, despite several requests and attempts.”
- “Some CCGs told us they would allocate to those organisations they had existing contracts with. As we did not have existing contracts with these commissioners, this meant we missed out.”
- “In one case, the funding has sparked a very helpful discussion and work towards collaboration in the future.”
- “Some of the CCGs clearly did not initially grasp the purpose of the ‘one-off non-recurrent funding’ and in some cases just put their non-recurring funding straight into their base budget.”

- “Leaving it to the discretion of individual CCGs did not make for equality across England.”

- “The CCG asked for specific projects and then rejected our request to part fund a second Paediatric Palliative Care Consultant.”

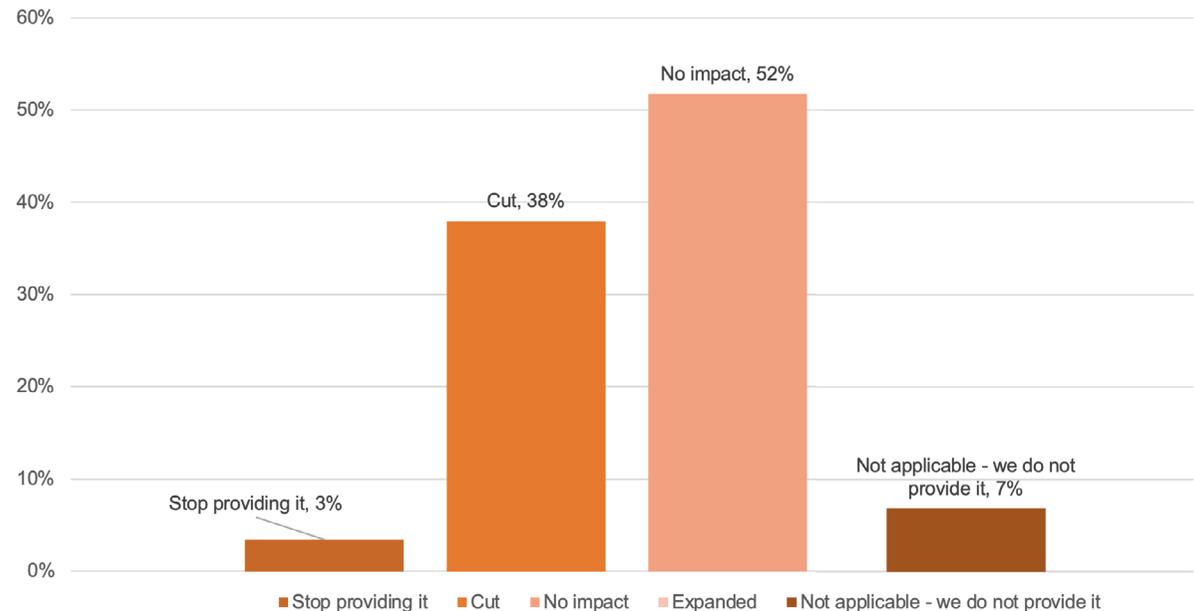
8. In this year’s children’s hospice funding survey, we asked children’s hospices to tell us what the impact on their services would

be if the Children’s Hospice Grant was not available from 2024/25 onwards. The results are very worrying.

End of life care

9. Nearly two in five (38%) children’s hospices would cut the end of life care they provide. One (3%) would stop providing it altogether. It would have no impact for just over half of children’s hospices (52%). 7% do not provide end of life care.

The predicted impact on end of life care if the Children’s Hospice Grant was not available from 2024/25 onwards



Manraj and Arjun's story

"He went to sleep forever. It was so peaceful."

Manraj's son Arjun had a brain haemorrhage in the womb. As a result, he needed complex, 24-hour care for the duration of his life. He received end of life care from his local children's hospice, Martin House. Manraj says:

"When he was 13 he was deteriorating and that is when the consultant referred us to Martin House Children's Hospice for respite. I remember the first day when I stepped into the hospice. I thought 'my child is coming here to die.' But it took a while for me to get my head around the fact that it was respite and it turned out to be such a wonderful thing. We were a family when we were there. The girls absolutely loved it and it was like a holiday for them. We miss that time together."

Arjun died on Valentine's Day 2020.

"One day I got a phone call at work. It was his school. They told me Arjun was very unwell, and I needed to come now. I knew then when I left my classroom that I wouldn't be coming back with my son still alive.

"I wanted him to die at the hospice, I didn't want the girls to see him



dying at home. He was getting more and more poorly at home and he had stopped eating and drinking. I was up 24/7 with him. I knew that I couldn't do it on my own any longer and he was moved to the hospice.

"We knew he would never come out. He was suffering and we knew the hospice would be the best place for him. And so he was moved the day before he died. We were with him all the time, family visited.

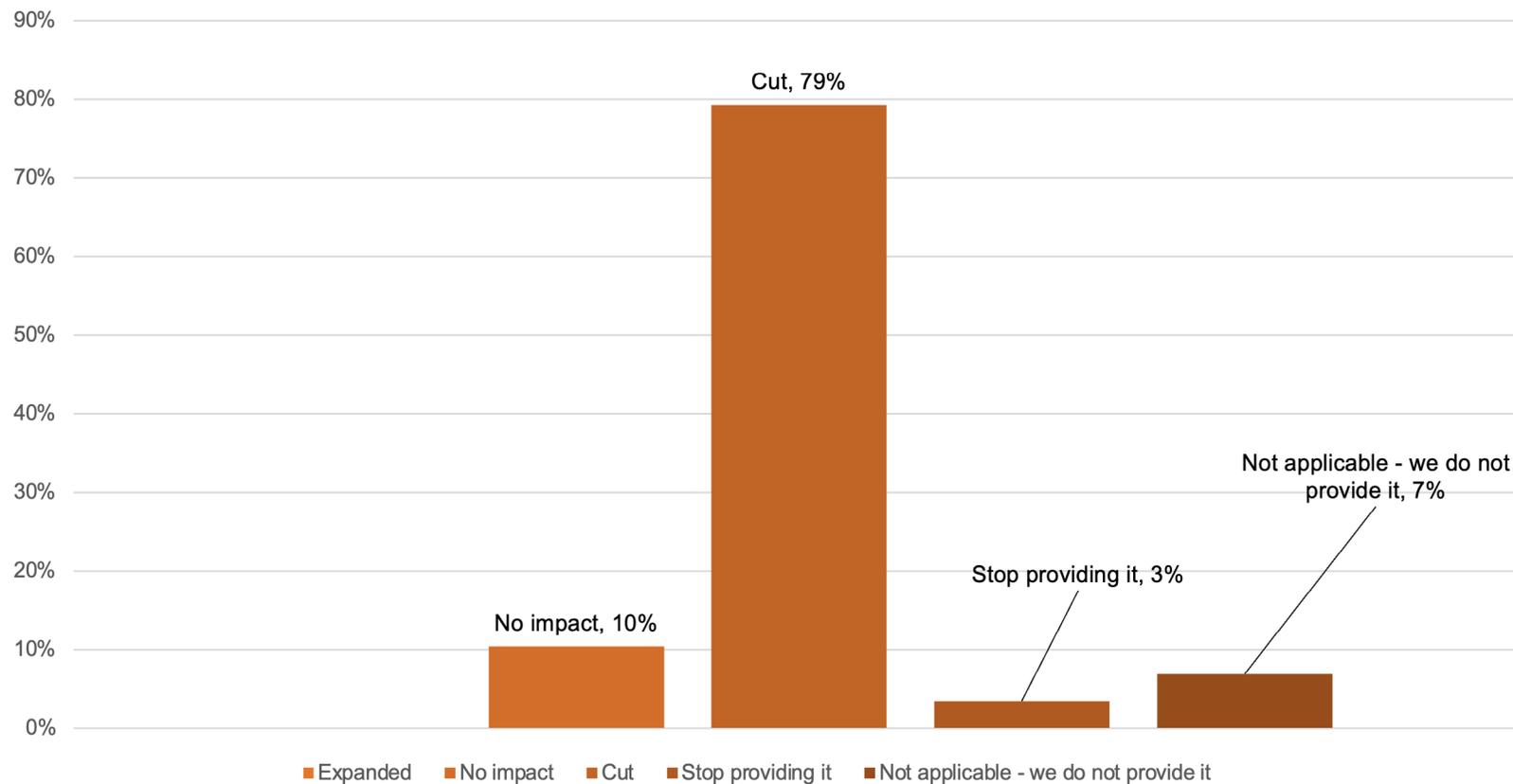
"On the 14th the girls came from school. We knew he wouldn't make it through the night. That's when we took our final photos together as a family. The girls went to another room to go to sleep and we cuddled in his bed. He passed away peacefully between us at 11.30pm."

"It was just as we wanted it. He took a breath and he was gone, it was so peaceful. He went to sleep forever."

Short breaks for respite

10. Nearly four-fifths (79%) of children's hospices would cut the respite or short breaks they provide. One (3%) would stop providing them altogether. It would have no impact for only one in 10 (10%) children's hospices.

The predicted impact on short breaks for respite if the Children's Hospice Grant was not available from 2024/25 onwards



Britt and Zoë's story

"I was broken and they put me back together again"

Shooting Star Children's Hospices have been part of the lives of Zoë and her parents Britt and Adrian since she was just eight weeks old. With her daughter now 15, Britt tells how Shooting Star Children's Hospices has been the place her family can turn to.

Zoë's birth was extremely traumatic. She died for six minutes in hospital before being resuscitated and having to have a tracheostomy fitted to help her breathe. Zoë has a genetic bone dysplasia disorder called OS-CS and used to require a tracheostomy to aid her breathing. She was later diagnosed with a rare complex neurovascular disorder, which causes chronic headaches and mini strokes.

The family were discharged from hospital shortly before Christmas but weren't granted any support from their local council, meaning it was solely Britt and Adrian left to look after their baby girl with all her complex needs. "I was slowly and surely sinking under, hardly sleeping and simply terrified something would happen to her. I went to some very dark places."

During this traumatic time, Cathy and Debbie, nurses from Shooting Star Children's Hospices, came to look after Zoë for a few hours at home. "I'd been having regular panic attacks, and when I walked into the living room, I just collapsed, and they took one look at me and arranged it so we could all come into the hospice to stay for emergency respite. They rescued us.



"I'm in no way exaggerating when I say they literally saved my life. My GP was so close to sectioning me, but she spoke to the team at Shooting Star Children's Hospices who said they could help us. We lived at the hospice for three months whilst I recovered and they campaigned for a care package for us so we could go home. They built my confidence to care for Zoë as well as be her mum.

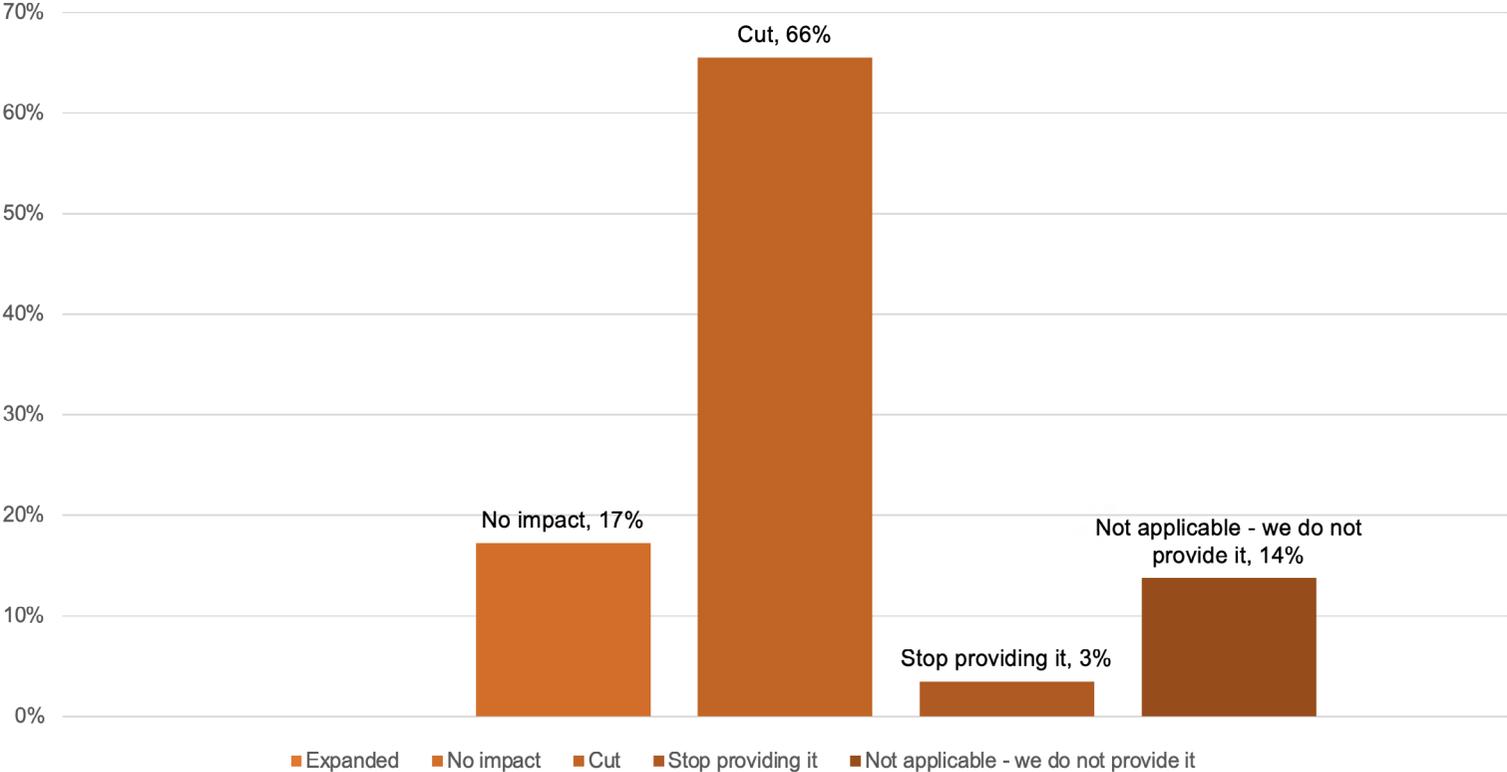
"I was in survival mode, she's going to live, I'm going to live and that was it. Then, I remember vividly, one day, during our stay I looked at Zoë and had this unbelievable rush of primeval love, like a tidal wave – and know it wouldn't have happened had it not been for Shooting Star Children's Hospices. They took us in, supported us, gave me tea, counselling, and time to recover and heal and realise I can do this. I was broken and they helped me put myself back together again."

Shooting Star Children's Hospices have continued to be a support to the family as Zoë's grown up. "When Zoë's day care closed, she was able to go to Sparkle Day Care for one day a week at the hospice, and she'd be able to stay for a weekend – we called them her spa breaks because she loved it so! Not only did we know she was loving it, but it gave us a chance to recharge and have a break."

Hospice at Home

11. Two-thirds of children’s hospices (66%) would cut the hospice at home services they provide. One (3%) would stop providing them altogether. It would have no impact for around one in six (17%) of children’s hospices. One in seven (14%) do not provide hospice at home services.

The predicted impact on hospice at home if the Children’s Hospice Grant was not available from 2024/25 onwards



Sam and Harry's story

"They keep my family together"

Harry spent the first six months of his life in hospital. Now 12, he has chronic lung issues, a severe curve in his spine, epilepsy, severe developmental delay and is registered blind. For his mum Sam, from Kent, caring for Harry is a full-time job. Throughout Harry's life, he and his family have benefitted from the hospice at home care that their local hospice, ellenor, provides.

"When I first heard the word 'hospice' I thought, 'oh my god, my child is going to die.' But I quickly came to learn that hospices aren't always about dying.

"ellenor were there before we were even discharged and I'll never forget the first time we met them. It was Christmas Eve and there they were, with a hamper, things to make a Christmas dinner with and presents for both Harry and my daughter. Since then, they've been the one constant in a very uncertain life."

As a single mum with two children, having hospice care directly delivered at home allows her to keep her family together. Every month, their nurse Tina visits for a check-in. She is always at the end of the phone to support Sam when she is worried or needs to talk.

"Before Harry, I didn't know that there this whole world existed. Having hospice care at home is a blessing. Tina rings me all the time to check in.

"When Harry has a chest infection, I will ring her and she will come right over. Not only does she do a full set of observations, she'll call the GP on my



behalf to get him antibiotics or tell me to take him to hospital."

Hospice at home helps keep children like Harry out of hospital where possible, saving the NHS bed spaces and money.

"ellenor is the step between a stay in hospital and staying at home. If those services weren't available, and we didn't have wonderful nurses like Tina, I honestly don't know what I'd do. They are invaluable and are my lifeline. To think that there could be a world without hospice at home care breaks my heart, because I know how much of a difference it has made to my family."

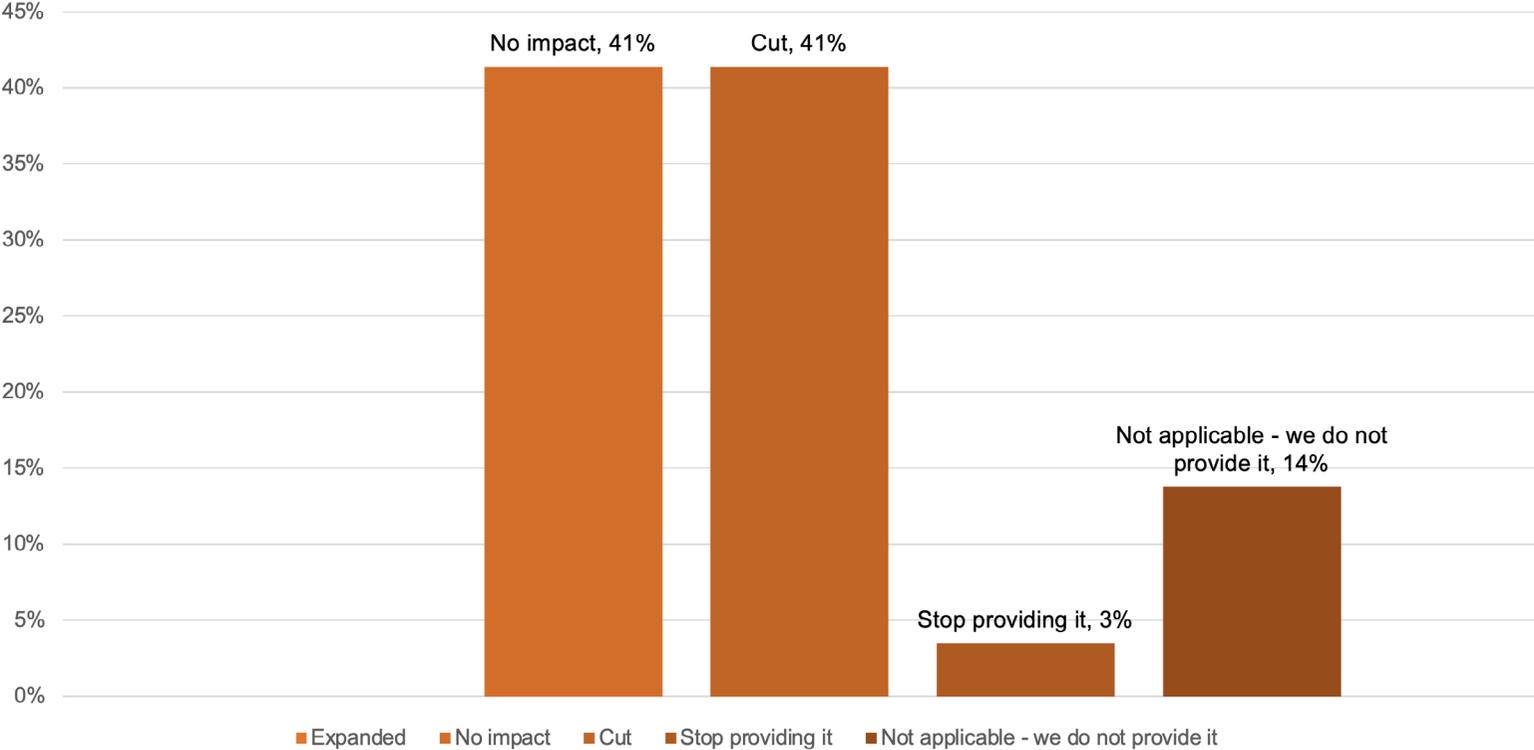
Over the years, Sam and Tina have formed an incredible bond. "Tina is bubbly, reassuring and always calms me down if I am panicking. Tina is Harry's nurse, and she is my friend. As soon as she comes through the door, I know everything will be okay. Because as well as she can look after Harry, she is a huge source of comfort to me and my daughter too."

As well as nursing care at home, ellenor has helped Sam, Harry and his sister make countless memories over the years. From music therapy and a visit to Disneyland Paris, to countless days out and introducing Sam to some life-long friends, ellenor has supported them every step of the way.

Symptom management

12. Two in five (41%) would cut the symptom management services they provide, including services to manage children’s pain. One (3%) would stop providing them altogether. It would have no impact for two in five (41%) children’s hospices. One in seven (14%) do not provide symptom management services.

The predicted impact on symptom management if the Children’s Hospice Grant was not available from 2024/25 onwards



Dan and Elisa's story

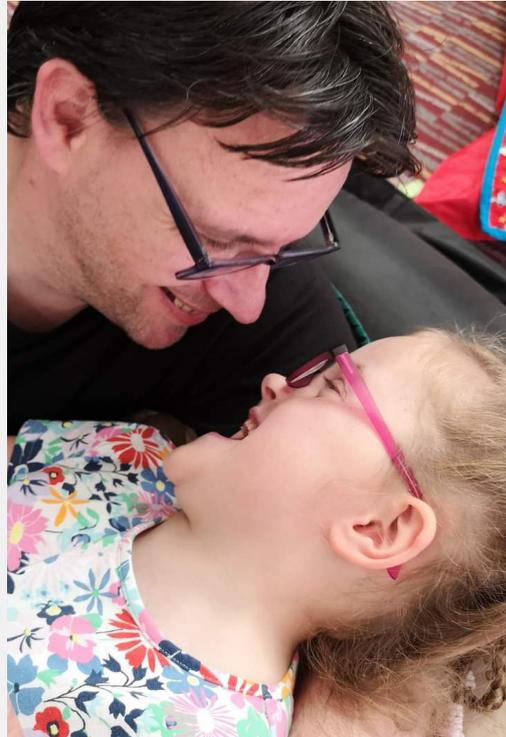
"They made a tremendous difference to her day-to-day life"

Dan McEvoy gave up his job as an IT analyst with Bournemouth University six years ago to look after his daughter Elisa, who was born with severe cerebral palsy. Elisa died at Naomi House Hospice in January 2023. Throughout her life she was supported by Julia's House Children's Hospice.

Elisa was deaf, struggled to swallow and had central and obstructive apnoea, which affected her breathing. The family, who live in Bournemouth, relied on their hospice to support them throughout Elisa's life.

Alongside their community nursing team, Elisa's symptoms were controlled by their hospice nursing team at Julia's House: "The hospice would follow her pain management protocol, with their first step always being positioning and physical comfort – 'hugs before drugs' – followed by her medicines."

The hospice would help care for her other symptoms including constipation and urine retention, said dad Dan: "There were several options to help Elisa with the



constipation and then Elisa was regularly catheterised."

The practical support would be learning what triggered a dystonic episode and how Elisa would show her discomfort and how to respond.

"The hospice would use sensory relaxation to help ease her symptoms and help her feel more relaxed: This would include foot massages, hand massages, pleasant smells that Elisa liked – all of these things would help to create a positive sensory input for Elisa and made a tremendous difference to her day-to-day life."

Impact on other services

13. Many children's hospices prioritise unplanned, emergency care such as end of life care and symptom management and will use their income, both statutory and charitable, to sustain them. Any cut in the grant will therefore have a profoundly negative impact on the other services they provide, even if they would not be routinely funded by the NHS. Children's hospices have told us that, if the Children's Hospice Grant was removed:

- nearly three-quarters (72%) would cut emotional and/or psychological support
- two-fifths (41%) would cut step-down care ²
- two-thirds (66%) would cut play therapy
- over half (55%) would cut music therapy
- nearly half (45%) would cut art therapy
- over half (52%) would cut practical support to families
- nearly half (45%) would cut hydrotherapy
- over half (52%) would cut counselling services.

“Whilst the guidance for commissioners, Service Specification, Commissioning Investment Framework and Ambitions documents are incredibly useful resources, Demelza has had to provide these to ICBs who were unaware of their existence. For some ICBs Demelza has not been able to even identify the lead for children's palliative care, making this even more of a concern for next year when ICBs will be responsible for allocating the Children's Hospice Grant. There is a real risk that ICBs will not allocate this to Demelza and services will therefore have to be cut.

“Where Demelza is currently supporting NHS teams in hospitals and in the community this will cease and the NHS will be required to fill these gaps without the charitable subsidy which Demelza also contributes so it will be more costly for the NHS.”

“The Children's Hospice Grant provides core funding to enable a children's palliative care service to be operational 24/7, 365 days per year. If this crucial funding is lost, staffing will need to reduce, the availability of the service will be impacted and children will instead be required to stay in hospital or be admitted or to receive NHS care at home. Demelza will not be able to respond to social care requests for safeguarding placements for children or when families are in crisis. This may lead to increased avoidable hospital admissions and if vulnerable families do not receive timely support, it will increase the numbers of children in the care system.”

Demelza Hospice Care for Children

² Step-down care provides children with help leaving hospital following prolonged hospital admission or major surgery. It can also support parents prior to the child going home.

Local NHS funding in England

14. The NHS Long Term Plan commits NHSE to match up to £7 million of CCG/ICB funding for children's palliative care, including children's hospice services, by 2023/24. The money is available to NHS and voluntary sector providers and is used to fund children's hospice and palliative care services. The funding amounts during this period have been:

- 2020/21: £2million
- 2021/22: £3million
- 2022/23: £5million
- 2023/24: £7million.

15. Despite this increase in funding available to local NHS organisations, children's hospices received, on average, nearly a quarter less funding from CCGs/ICBs in 2022/23 compared to 2021/22: children's hospices received an average of £532,923 from CCGs and ICBs in 2022/23, a 23% decrease compared to the £688,830 they received from CCGs in 2021/22.

16. This represented £1 in every £8 of their charitable expenditure (13%), down from the £1 in every £5 (20%) that CCGs funded in 2021/22. One children's hospice did not answer our question about local NHS funding.

17. Local CCG/ICB funding for individual

children's hospices varied significantly:

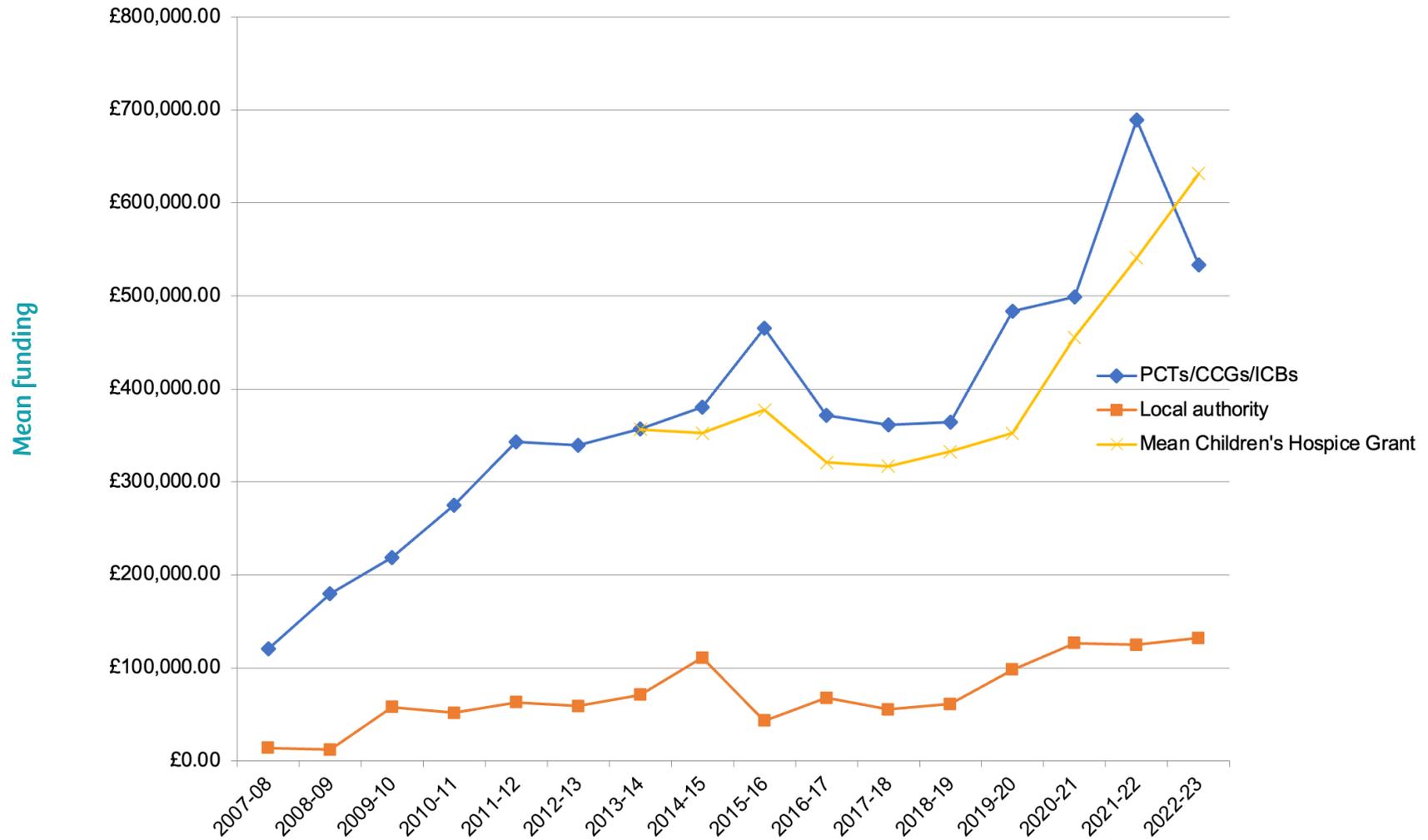
- Ten, equal to just over a third (34%) of children's hospices, saw their CCG/ICB funding decrease between 2020/21 and 2021/22.
- Ten (34%) received greater CCG/ICB funding.
- Nine (31%) did not answer this question.

18. Local CCG/ICB funding also varied in terms of the proportions of children's hospices' charitable expenditure that it represented:

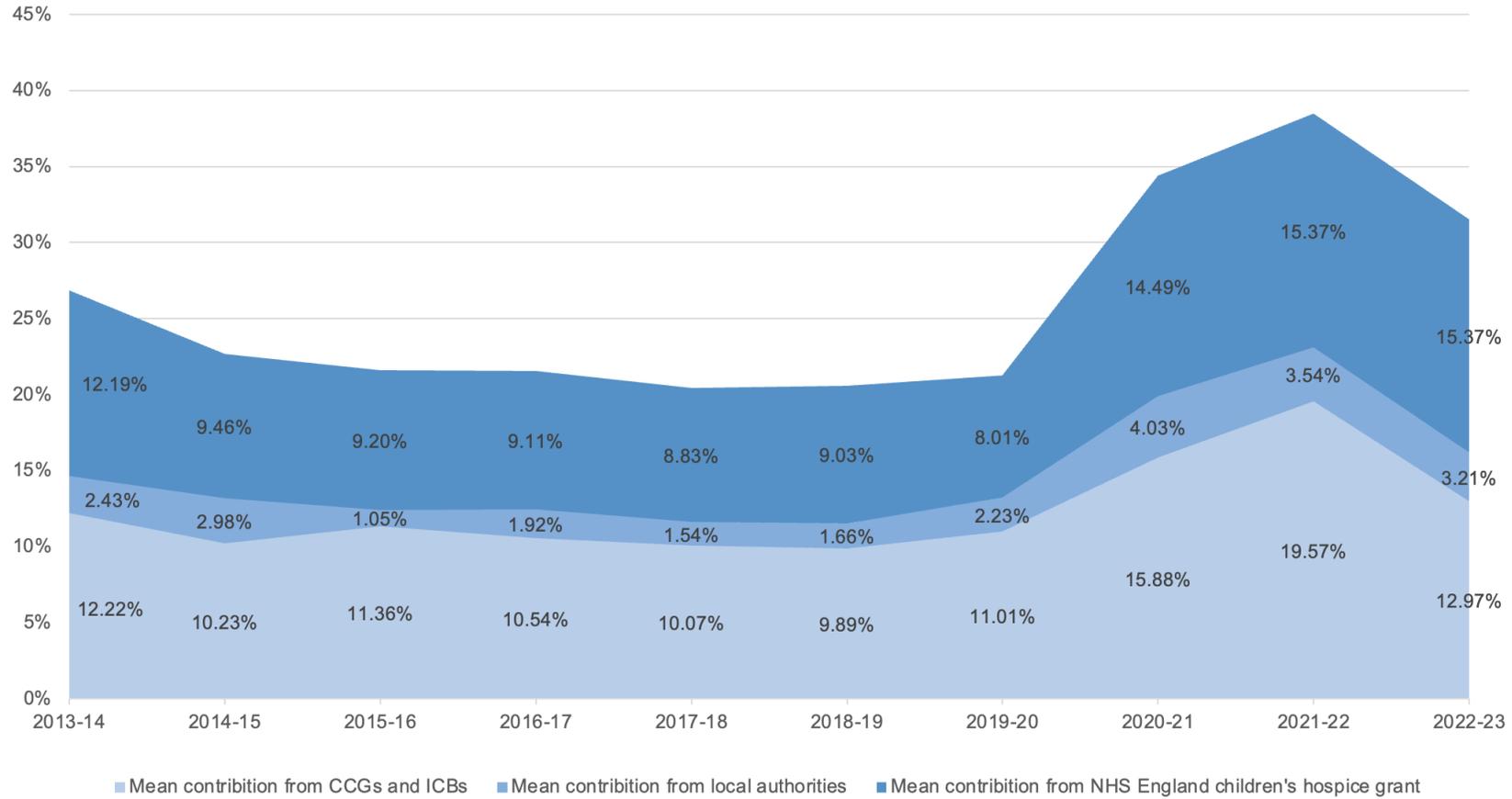
- One in 10 (10%) children's hospices received over 30% of their charitable expenditure from CCGs/ICBs.
- One in three (34%) received 5% or less of their charitable expenditure from CCGs/ICBs.
- One children's hospice did not answer this question.

19. Children's hospices expected their average funding from ICBs to increase by 4% to £552,229 in 2023/24. Over two-thirds of children's hospices (69%) expected their ICB funding to increase, compared to seven (24%) who expected it to decrease. One (4%) expected no change in their ICB funding. One did not answer the question.

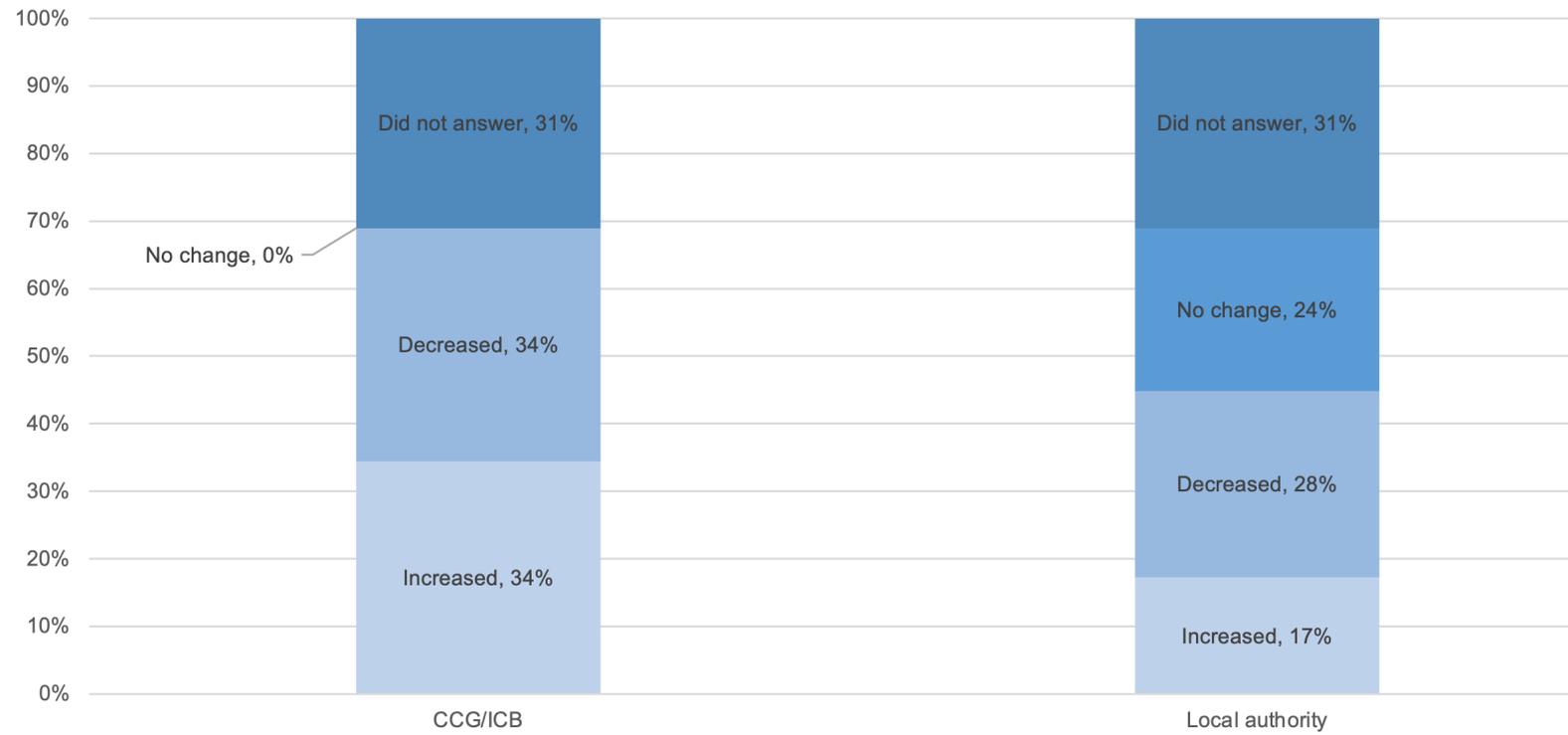
Mean local funding for children's hospices in England 2007-23



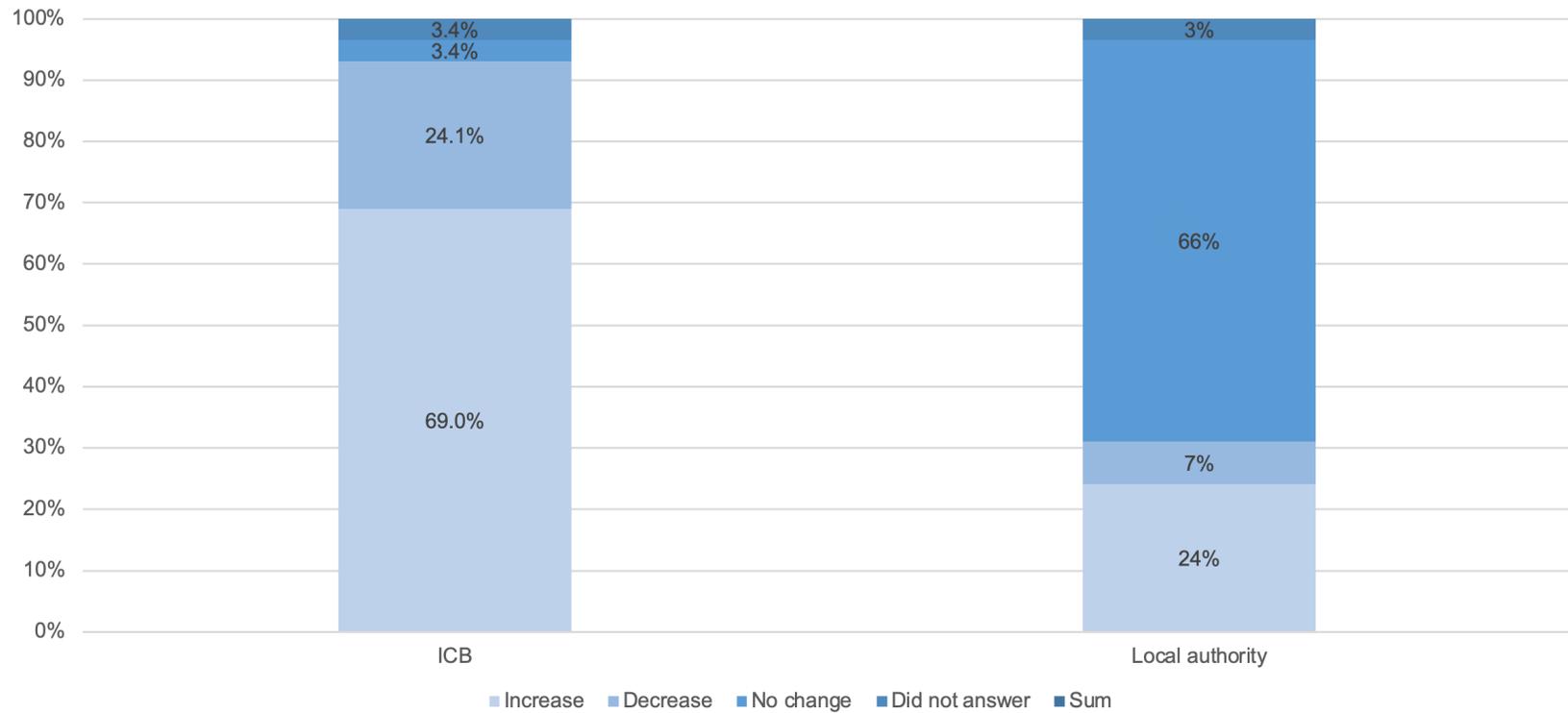
Proportion of children's hospices' charitable expenditure reimbursed by the state 2014-23



How has your level of funding from statutory sources for 2022/23 changed compared to 2021/22?



How do you expect your level of funding from statutory sources for 2023/24 to change compared to 2022/23?



Local authority funding in England

20. Of the 28 children’s hospices in England that told us how much they received from their local authorities for providing care to seriously ill children, they received an average of £132,017 each. This represented a 5.8% increase on the £124,784 reported in 2021/22 and represents a small proportion (3.2%) of the charitable expenditure incurred by children’s hospices in 2022/23. It is also small considering the proportion of children’s hospice activity that short breaks for respite represents – and the fact that local authorities have a legal duty to ensure disabled children can access short breaks.

21. Despite the average increase in local authority funding across England, funding varies widely between children’s hospices. Five children’s hospices (17%) reported a cut in local authority funding between 2020/21 and 2021/22. Eight (28%) reported an increase. Seven (24%) reported that their local authority funding did not change. Nine (31%) did not answer the question.

22. This means that over half (52%) of children’s hospices reported a cut or freeze in their local authority funding between 2021/22 and 2022/23.

23. Average local authority funding for children’s hospices is expected to increase by 29% to £170,564 in 2023/24 to compared to 2022/23. However, individually, two thirds (66%) of children’s hospices expect their local authority funding not to change between 2022/23 and 2023/24. A quarter (24%) expect an increase and 7% expect an increase. One children’s hospice did not answer this question.

Qualitative feedback from children’s hospices about how they are funded by the state

“We have long-established relationships with our commissioners working across six ICBs. We have a variety of contracts and grant agreements. However, these are for a small proportion of the overall work we deliver.

“In addition, we also provide commissioned beds for individual children who require specialist clinical support in the short-term. We work closely with NHSE and health partners in the delivery of collaborative projects. The Children’s Hospice Grant funding is an integral part of our overall funding work.”

Acorns Children’s Hospice

“The amount hospices save the NHS, not just in terms of end of life care but community, symptom management, respite and emotional support is immense.

“Our concern is about future funding from the ICB/Integrated Care Systems (ICS’s). The message from them is that they have no funds yet our services provide the lead on end of life / respite for children in our care.”

Alexander Devine Children’s Cancer Trust

“Local commissioning arrangements have allowed Claire House to develop service provision specifically in unplanned respite, outreach end of life care and perinatal care. We are currently in the process of establishing a single contract and single reporting format for all places within an ICB

footprint, with a goal of negotiating a lead commissioner for children's palliative care for the ICB."

Claire House Children's Hospice

"Changes to commissioning arrangements with the move to ICBs and ICS's have meant Demelza has needed to invest time and money in attempting to develop relationships with new commissioning organisations, which are not yet in a mature stage of development. The all-age palliative care agenda means Demelza needs to frequently participate in meetings which are primarily about adult palliative care, with a constant need to raise the importance of consideration for children's needs and services. Commissioners understanding of children's palliative care varies considerably, which is of particular concern given the move to ICBs of the Children's Hospice Grant.

"The time and resources required to engage with the four ICB's/ICS's in Demelza's catchment area is a significant investment, with little or no return in terms of statutory funding."

Demelza Hospice Care for Children

"Since 2021/22, we have been working closely with our local ICB to create a more cost reflective tariff for the hospice. In 2022/23, we signed a contract variation with our local ICB confirming the additional tariff lines, including standard and high complexity tariffs. This has been instrumental in increasing the statutory funding which has in turn enabled us to provide care to more children in our local area.

"In 2022/23, we have provided regular social care respite to a child. This will continue in 2023/24 and we will be providing this also to another child."

Haven House Children's Hospice

"Havens Hospice only receives approx. 20% commissioned income. We have excellent working relationships with our commissioners and during 2022/2023 we worked together to review our current contracts to ensure that there is a clearer understanding of which services are included within the 20%. We have undertaken a review of Children and Young People Service which has highlighted the need to further expand services to reach all of the families that need our care. There is therefore a growing need and widening disparity between provision and commissioned income.

"Local authority commissioning has been challenging in 2022/23 with excessive monitoring, reporting and management support for short-term, small investments. This has called the value of this income into question.

"Across the NHS and local authority, it has been disappointing that despite the ICS aligning health and social care, the commissioning streams have been disjointed and difficult to navigate.

"Collaborative commissioning has been beneficial during 2022/2023 with system-wide approaches being funded for the benefit of the local population. This has forged excellent working relationships, stopped silos within services and created greater opportunity for innovation."

Havens Hospices

"We have seen a much greater engagement from the local ICB with opportunities and support to bid for additional funding streams."

Helen & Douglas House Children's Hospice

"We have never understood why we are one of the worst Government-funded

children's hospices in England, other than the 'postcode lottery' of devolved funding decisions. Is it because we provide more respite care, which for children with less complex but still palliative need is deemed less 'health' and more 'social care', despite its well-researched impact on family wellbeing and parental health? No-one in Dorset ICS/ICB can give us an answer. "

Julia's House Children's Hospice

"We receive virtually no confirmed funding from Hampshire and Isle of White ICB and very little funding from the local authority. We have some funding from Dorset and Wiltshire."

Naomi House & Jacksplace Hospices

"We have set a target within our strategy to gain 60% of care expenditure from statutory sources. We believe this is fair funding for the care and bed nights we provide. To date, funding has been very patchy and is down to individual commissioners and our relationships with them."

Noah's Ark Children's Hospice

"We continue to receive the funding for our overnight respite services as individual placement agreements for individual children who live in five ICB areas and 17 local authority areas. Despite significant increase in local engagement, it remains very difficult to secure contracts for this provision."

Shooting Star Children's Hospices

"There is no equity in the funding from place/local authority areas – of the six we cover, we are only funded by two.

"A huge amount of work (funded one day

per week) has taken place – taking the lead for developing a children and young people's palliative and end of life care strategy and delivery plan and, in turn, service development. This has not led to increased contract funding, but has placed the hospice in a positive position when developing future services."

St Andrew's Hospice

"We have sustained an increased rate per night from our commissioners which has had a very positive impact."

St Oswald's Hospice

"Uncertainty. While we have good relations with the ICB in one area, we are seen as a 'nice to have service' rather than essential service."

Jessie May

"We are working as part of the West Yorkshire collaborative to secure sustainable funding for the future. We have a commitment in place from 2024/5 onwards over five years to resolve this and are working on funding formulas to agree with the system. Doesn't help for the year ahead though."

Forget Me Not Children's Hospice

"We agreed a project with (our) ICB where we trial offering additional respite and they can ensure they are happy with the service/provision we offer for the charges we have proposed before they commit to a longer-term contract for ongoing funding."

James Hopkins Trust

Income

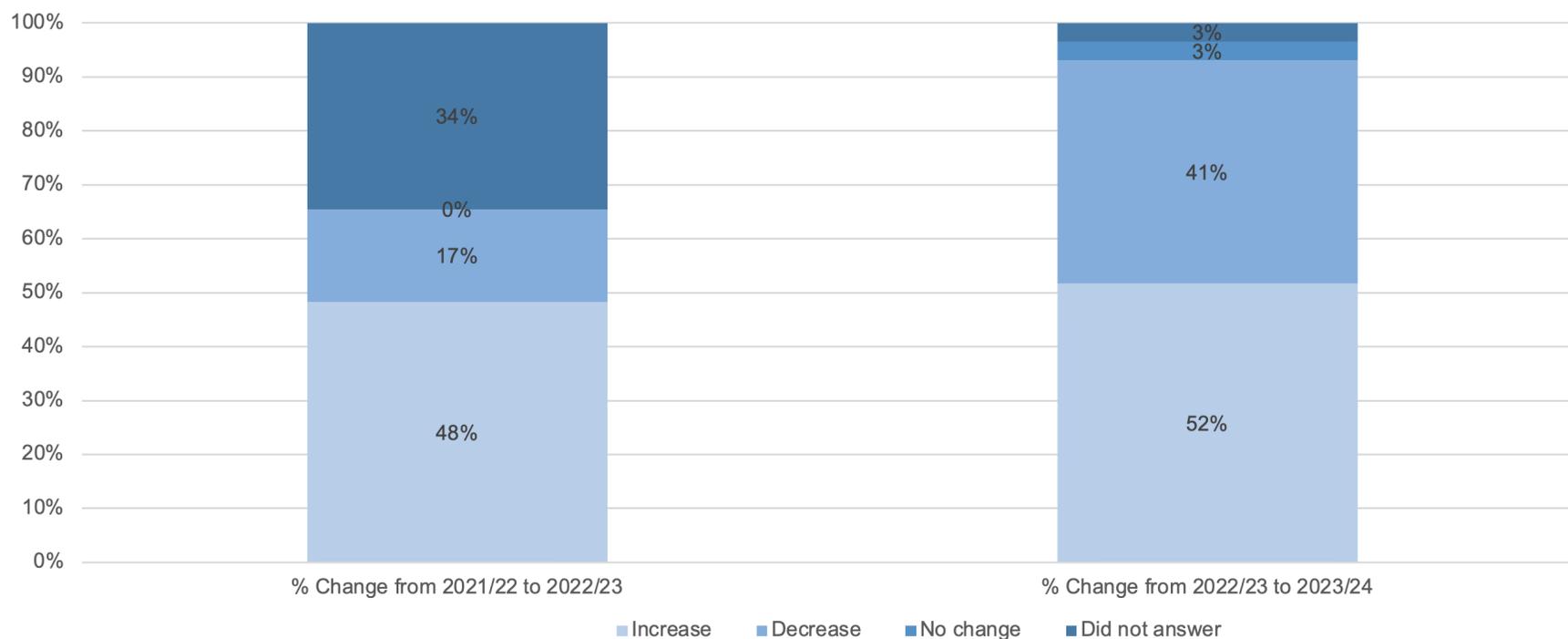
24. Among the 28 children's hospices who told us about their total income in 2021/22, their average income was £7,320,471, a 2% increase on the average of £7,183,888 received in 2021/22.

25. Income varied between children's hospices, however. Fourteen (48%) children's hospices reported that their income increased between 2021/22 and 2022/23. Five (17%) reported a reduction. Ten (34%) did not answer this question.

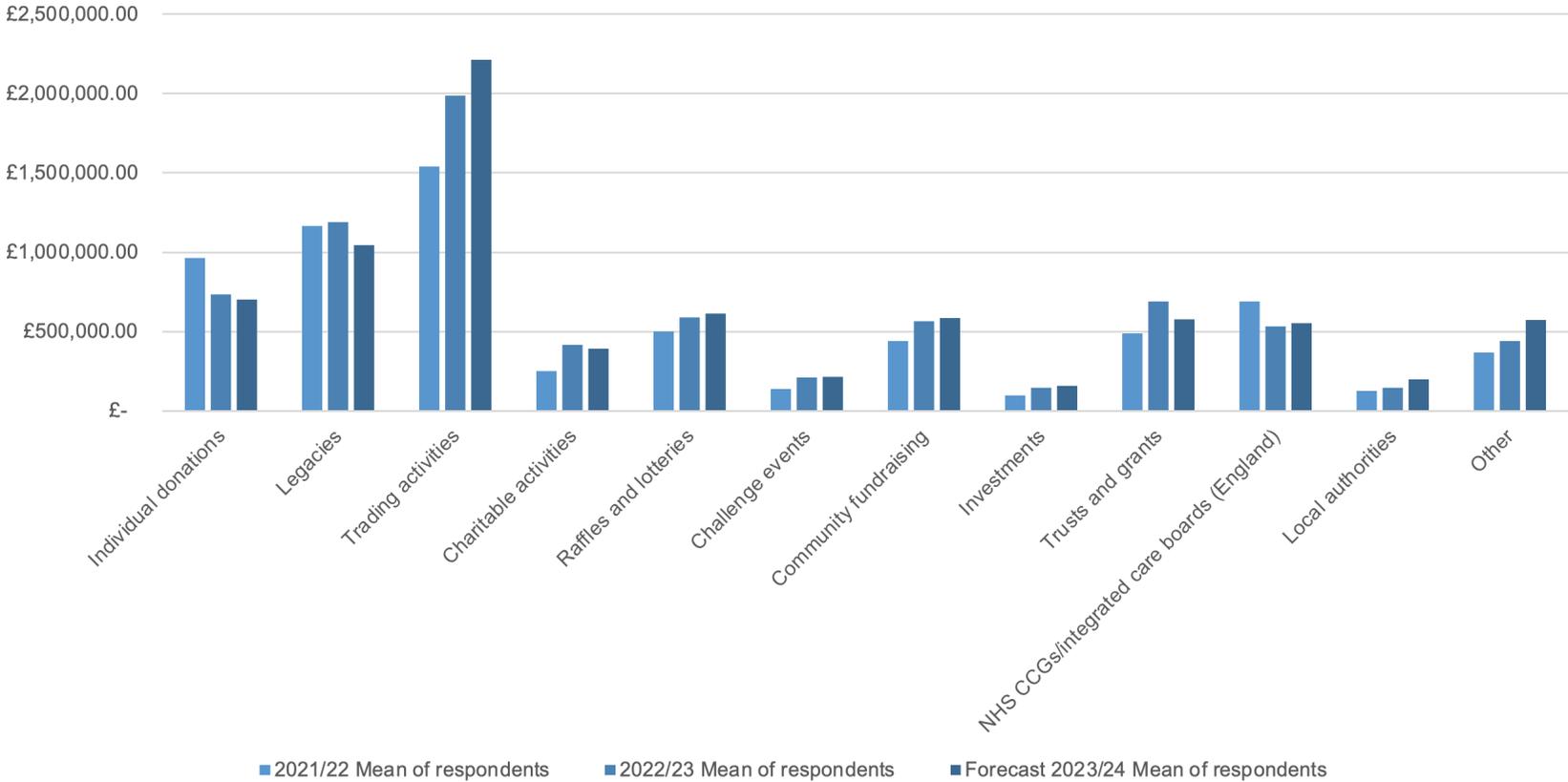
26. On average, children's hospices expect their total income to increase by 2% to £7,492,849 in 2023/24.

27. Predicted income also varies between children's hospices. Fifteen (52%) of children's hospices expect their income to increase between 2022/23 and 2023/24. Twelve (41%) expect a reduction and one (3%) predicts no change. One did not answer this question.

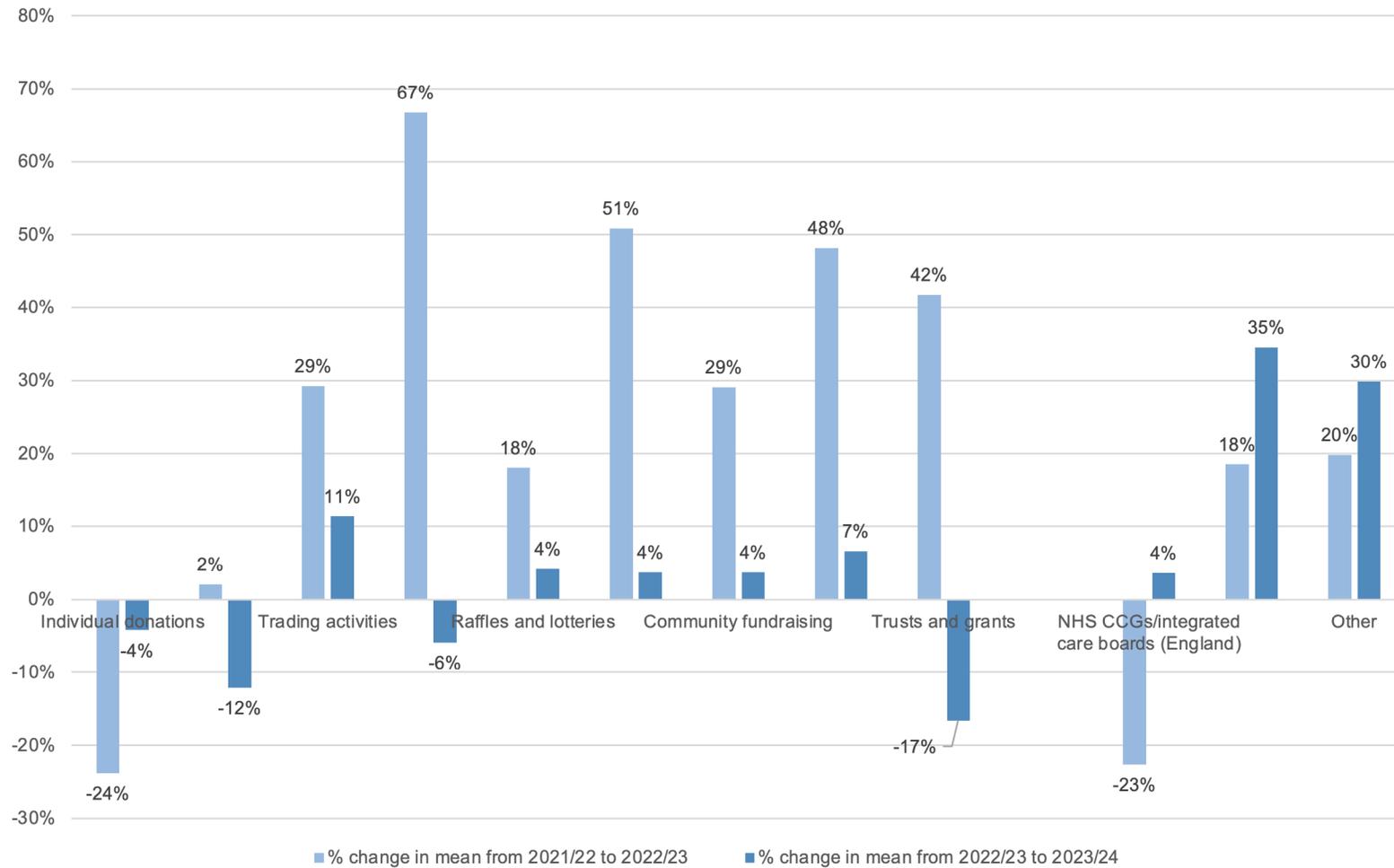
Change in children's hospices income 2020-2024



Mean children's hospice income by source 2019-2024



% change in mean children's hospice income by source 2021-2024



Income by source

28. These increases were driven by trading activity, which grew on average by 29% from £1,538,235 in 2021/22 to £1,987,656 per children's hospice in 2022/23. This source represented just over a quarter (27%) of children's hospices' income on average, compared to 21% in 2021/23. Children's hospices expect their trading activities to increase again on average by 11% in 2023/24.

29. Average legacy payments grew by 2% from £1,165,308 in 2021/22 to £1,189,330.56 per children's hospice in 2022/23. They represented 16% of children's hospices' average income in 2021/22. However, on average, children's

hospices forecast them to fall by 12% to £1,045,126 in 2023/24, when they are expected to account for 14% of children's hospices' average income.

30. Worryingly, average individual donations to children's hospices fell again, this time by 24% from £963,348.95 in 2021/22 to £733,384 in 2022/23. On average, children's hospices expect them to fall again to £702,243 in 2023/24, representing just 9% of children's hospices' income.

Charitable expenditure

31. On average, children's hospices reported that their charitable expenditure grew by 13% from £3,610,970 in 2021/22 to £4,077,340 in 2022/23.

32. Nearly all (93%) of children's hospices attributed the rises in the charitable expenditure they incurred to the higher costs of recruiting and retaining staff. Two-thirds (66%) attributed them to higher energy prices and 69% to the higher costs of other consumables.

33. Just over half attributed their increased charitable expenditure to an increase in activity.

34. Children's hospices expect their average charitable expenditure to grow again by over one-fifth (21%) between 2022/23 and 2023/24 to £4,932,904.

35. Separately, Hospice UK has found that, in terms of children and adult hospices' energy costs:

- Energy bills are set to increase by £29 million over the next year.
- Nearly nine in ten (86%) hospices will have come to the end of a fixed price deal by the end of the year.
- Global events mean new deals are increasing in price by up to five times.

36. At the end of March, the UK Government

reduced support for hospices with their energy costs. Hospices are now only receiving a modest discount – the same level as a pub or restaurant, and less than zoos and museums. But unlike businesses who can pass costs onto customers, hospices will have to fundraise more from local communities to cover this.

37. The cost of paying hospice staff is also rising. Hospices recruit from the same pool of staff as the rest of the NHS, meaning they need to try to match NHS salaries. When NHS wages go up – as is likely given current negotiations – hospices will again have to find funds from their local community.

38. Children's hospices are committed to paying their staff a fair wage. However, Hospice UK has calculated that to match the NHS pay offers currently on the table around the UK would cost children's and adult hospices around £120 million extra in 2023/24.

39. Together for Short Lives has previously found that children's hospices in England have higher vacancy rates relative to the NHS: in March 2022, the average vacancy rate for non-medical care and support roles (including nurses) equivalent to Agenda for Change bands 2-9 for children's hospice charities in England was over 18%.

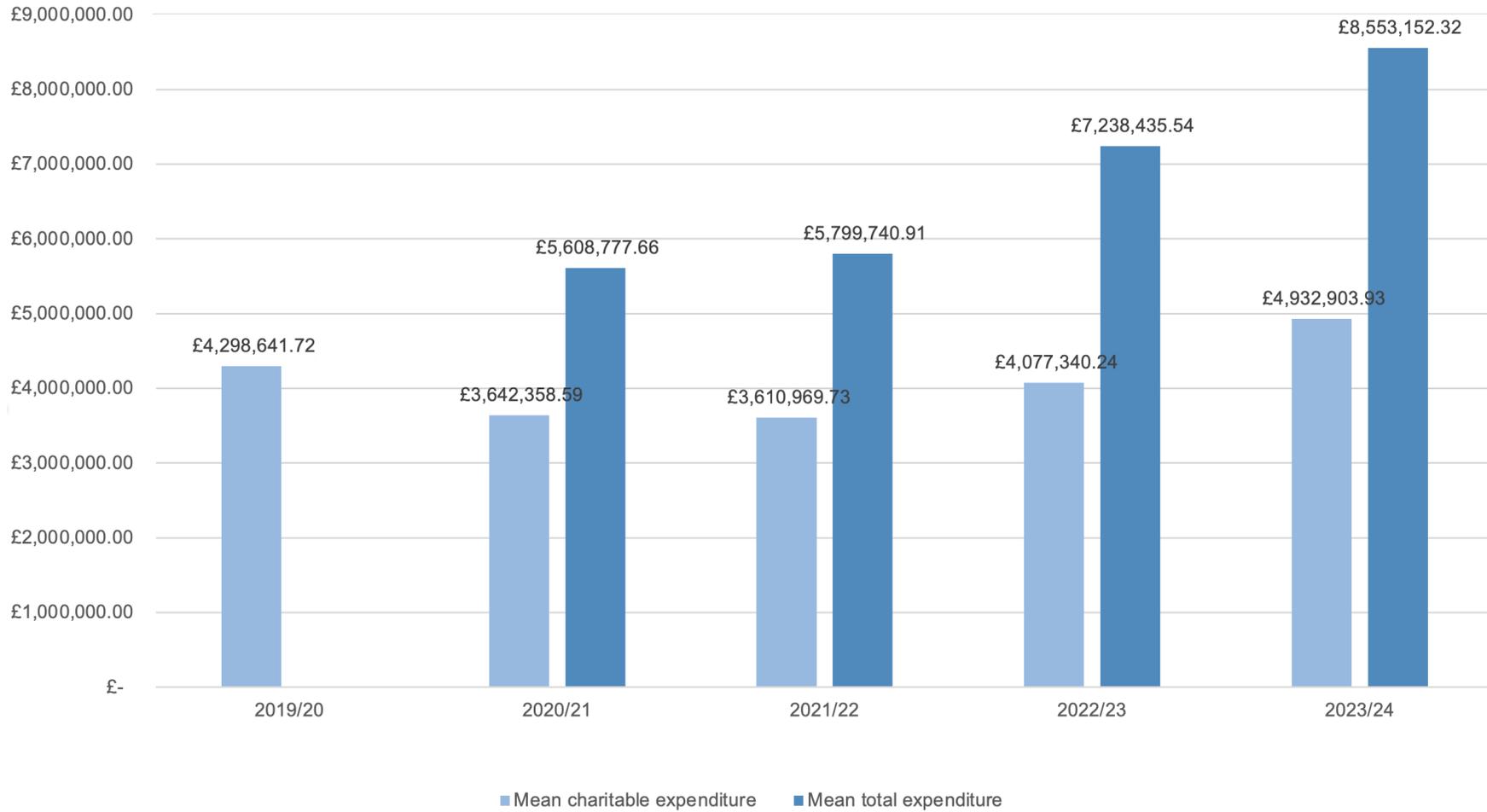
40. Children's hospices now rely on the larger Children's Hospice Grant to help them meet their growing costs.

“Inflation has had a massive impact on the cost of living for our staff and we have had to provide additional support. Increased energy costs, consumables and supplier contracts have also impacted both our charitable expenditure and total expenditure.”

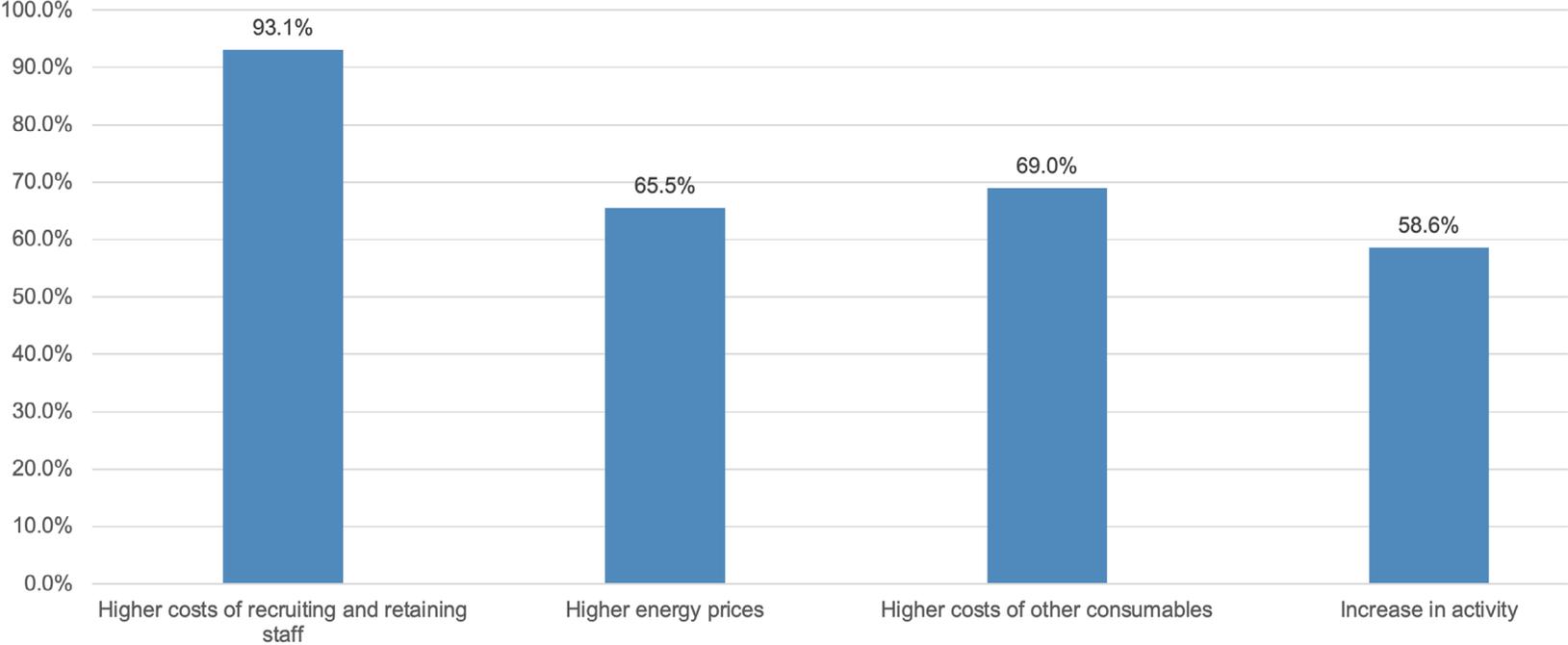
- Keech Hospice Care

³ Hospice UK. 2023. Hospices facing mounting cost pressures. Available to download from: <https://www.hospiceuk.org/latest-from-hospice-uk/hospices-facing-mounting-cost-pressures>

Mean charitable and total expenditure by children's hospices 2019-2024



If your charitable expenditure increased between 2021-22 and 2022-23, please tell us why that was



Total expenditure

41. Children’s hospices’ total expenditure, which includes fundraising costs, rose on average by 25% from £5,799,741 in 2021/22 to £7,238,436 in 2023/24. On average, children’s hospices expect it to rise again by 18% to £8,553,152 in 2023/24.

Balance between total income and total expenditure

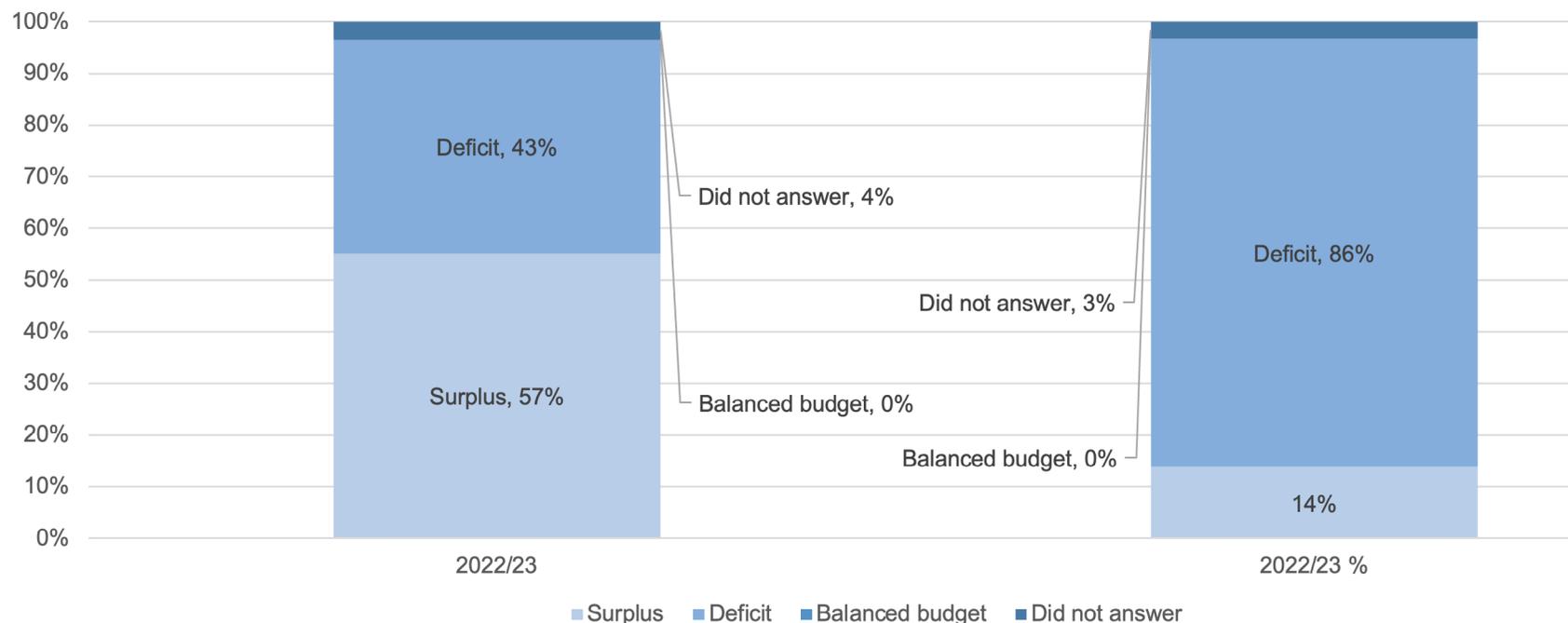
42. Overall, over half (57%) of children’s hospices reported a net surplus in 2022/23. 43% of children’s hospices reported a net deficit. One did not answer this question.

43. However, over four-fifths (86%) of children’s hospices forecast a net deficit in 2023/24. Just 14% expect to make a surplus.

44. Taking all respondents’ surpluses and deficits into account, and on average, children’s hospices made a surplus of £82,035 in 2022/23. However, in 2023/24, on average, children’s hospices expect to report a deficit of £1,060,303 per children’s hospice.

Extrapolated across all 34 children’s hospice organisations in England, this would represent a shortfall of £36,050,313.

% of children’s hospices reporting surpluses, deficits and balanced budgets



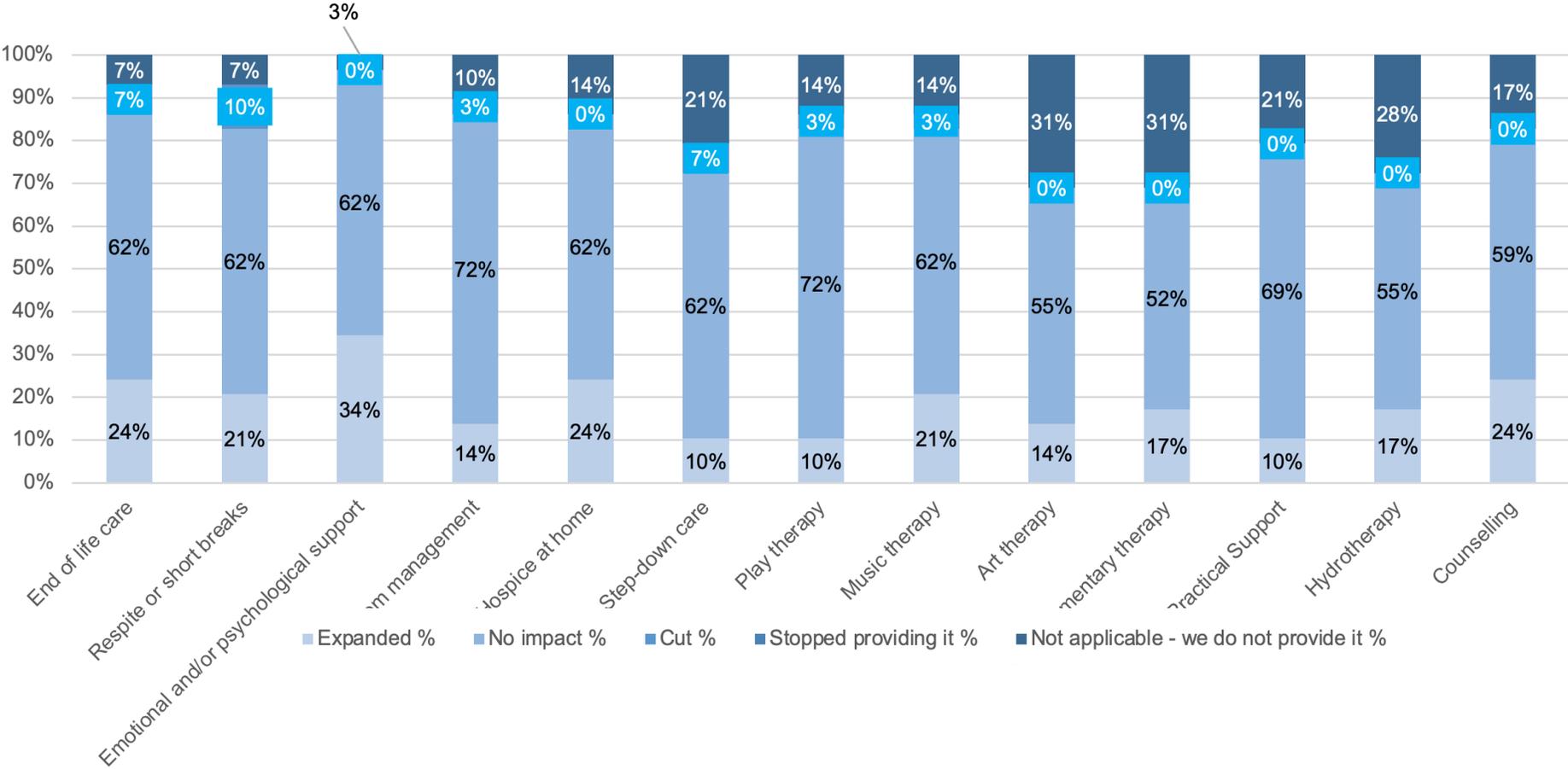
Impact of funding changes on services

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

46. It is encouraging that a quarter (24%) of children's hospices expanded their end of life care in 2022/23 compared to 2021/22. A fifth (21%) expanded their respite or short breaks and a quarter (24%) expanded their hospice at home services.

47. However, it is concerning that one in 10 (10%) children's hospices cut short breaks for respite as a result of funding changes between 2021/22 and 2022/23.

Impact that changes in funding between 2021/22 and 2022/23 have had on the services provided by children's hospices



“We have been extremely concerned by funding issues in relation to COVID and lack of Government funding for the future. The demand for our service has grown and referrals are up. We know how valued and vital the service is to families. We are looking at a £900k budget loss for 2023/24 and expect to cover this from reserves.”

Alexander Devine Children’s Cancer Trust

“Demelza does not have any on-going annual contracts with ICBs to provide children’s palliative care and therefore relies on funded placements for individual children. This is unpredictable as it is dependent upon need, which fluctuates. During 2022/23, this income was reduced from £883,783 to £278,507 despite Demelza providing services to more children, because there were fewer children who received care from Demelza for prolonged periods. This demonstrates the unpredictability and lack of sustainability in this funding model.

“Whilst Demelza is currently fortunate to have significant reserves due to generous legacies, these are being used to fund core services, which is not sustainable in the medium or long-term. Unless this changes, Demelza will be forced to make cuts to services.”

Demelza Hospice Care for Children

“The impact of an increase in statutory funding has enabled us to develop and sustain NHS integrated posts. The matched funding has enabled us to increase the education and training we provide to professionals and we were able to carry out a detailed needs assessment jointly with our local ICB and another local hospice.”

Haven House Children’s Hospice

“We have spent considerable effort over the past four years identifying and applying for additional funding from grant givers and trusts and it is this that has allowed us to expand our services, especially in regards to transition, community work and end of life care. Our statutory funding in this time has remained static and will in fact decrease due to the NHS England grant reduction from 2023/24 onwards. Continuing to offer these services may be wholly dependent on retaining the grant funding that we attract or potentially utilising our reserves.”

Hope House Children’s Hospice

“We have experienced challenges in recruitment, leading to a reduction in in-house care. We believe this is due to a number of reasons, including the difficulty in mirroring/being directly competitive with Agenda for Change, due to reduction in income. We are in the early stages of developing an at-home outreach service, which will at first be grant-funded.”

St Andrew’s Hospice

“We have recognised that families need more support in different ways to remain resilient. This has meant that our short breaks are now responsive to need rather than given out on a rota and are managed by unqualified staff with the support of a nurse in charge.”

Forget Me Not Children’s Hospice

Active caseloads

48. On average, children's hospices' active caseloads have decreased slightly by 7% from 292 in 2021/22 to 272 in 2022/23.

49. However, children's hospices reported greater levels of activity in 2022/23 across all the types of care and support that should be funded by the NHS.

50. On average, children's hospices provided:

- end of life care to 4% more children (21 per children's hospice, compared to 20 in 2021/22)

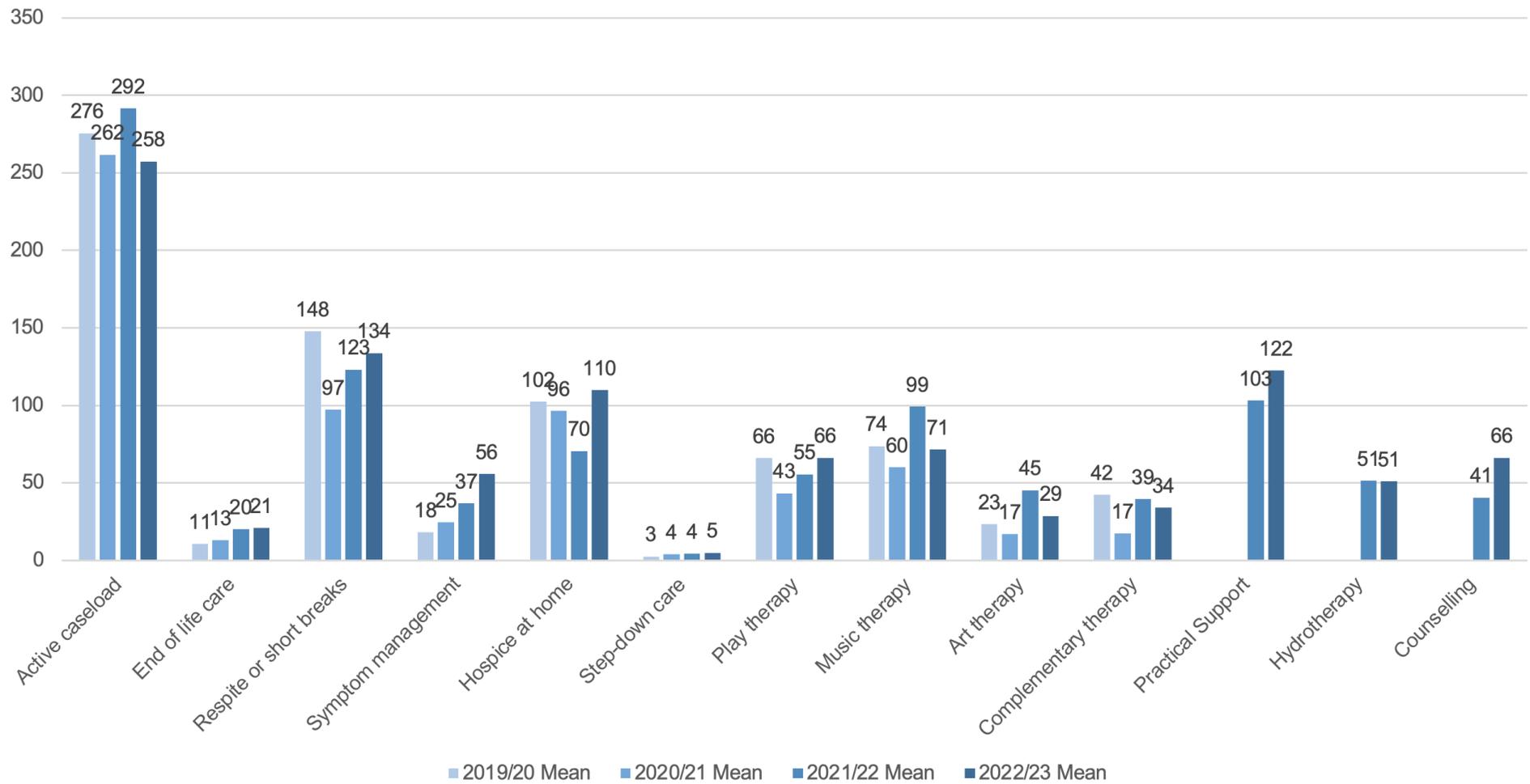
- symptom management care to 51% more children (56 per children's hospice compared to 37 in 2021/22)

- short breaks for respite to 9% more children (134 per children's hospice compared to 123 in 2021/22)

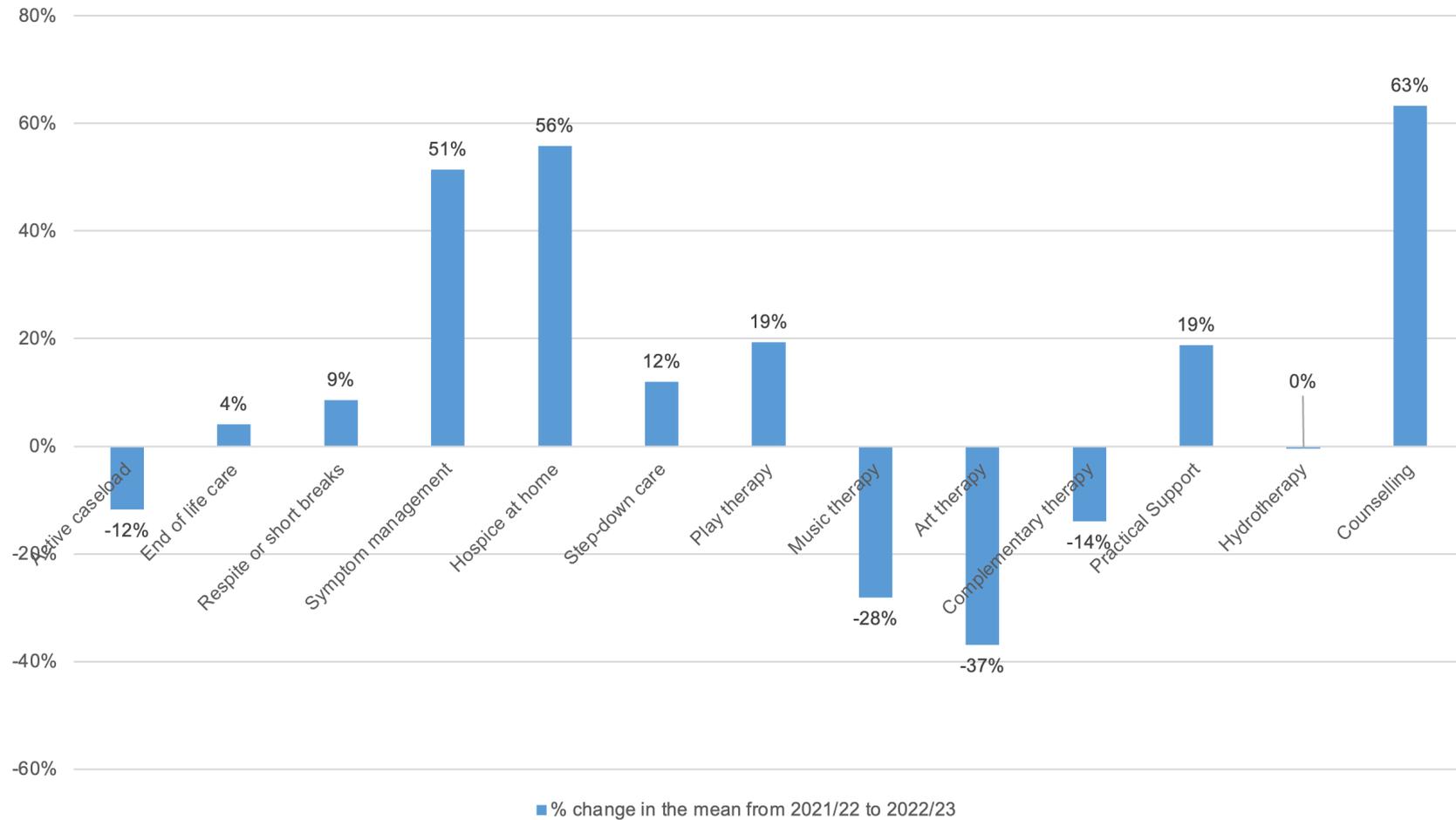
- hospice at home to 56% more children (110 per children's hospice compared to 70 in 2021/22)

- step-down care to 12% more children (five compared to four in 2021/22).

Mean caseloads 2019/20 and 2022/23



% change in mean caseloads from 2021/22 to 2022/23



The impact that children's hospices have on their wider local and/or regional health and social care system

51. It is clear from the qualitative feedback below that children's hospices have a positive impact on their local health and care systems in return for the funding they receive:

“Acorns services are 24/7. We have access to medical and specialist clinical staff able to provide symptom management advice and direct care out of hours, through weekends and bank holidays via this service. Thus preventing admissions to hospital for children whose symptoms require active management.

“Our teams are able, through anticipatory planning and partnership working with other health providers in the sector, to ensure children stay in their own homes or have a pathway into the hospice. Equally, we have embedded hospice staff into the tertiary centre which enables very clear discharge pathways to be activated in an effective and responsive way ensuring children receive the appropriate care required in their homes or in the hospice, freeing up hospital beds and releasing hospital resources for other priorities.

“Our specialist family services teams also work 24/7 providing pre and post bereavement support working with families at times of crisis, reducing a sense of isolation and providing coping strategies preventing family breakdown and better outcomes for the child and children in the family.”

Acorns Children's Hospice

“We are able to provide 7000+ hours of respite in hospital, schools and community, 60+ overnight stays of respite at the hospice, 17+ hours of specialist care, 150+ children supported. Fourteen children

received end of life care, we held 20 events and socially supported bereaved families and 32 families received support from us for the first time. All of this has had a huge impact for the NHS, in all aspects of care that these children and their families require.”

Alexander Devine Children's Cancer Trust

“If the NHSE children's hospice grant does not reach us in full or at all, this would have a significant impact on the core respite we can provide to children. In recognising that this is the final year of the grant being centrally distributed, and the uncertainty surrounding its continuity beyond 2023-24, we have added the grant to our risk register as it could have a serious impact on our ability to provide core respite to children.

“Having been able to secure and build strong local commissioning of our unplanned respite and community-based end of life care services, any significant cut to central or locally commissioned funding will seriously impact our provision of specialist and core services for the children and families of Merseyside.”

Claire House Children's Hospice

“The Children's Hospice Grant forms a vital part of all services that Demelza offers.

“Demelza is an essential part of the palliative and end of life care offer for children and young people across South East London and into South West London, across all of Kent and Medway and East Sussex.

“Data suggests there are 8,473 children and young people (CYP) that fall under

our demographic of which Demelza has a caseload of 667. We work closely with hospitals providing specialist Tertiary Services, in particular the Evelina Children's Hospital Palliative Care Team and more local acute trusts, social services, local authorities and maintained special needs schools.

“An organisation such as Demelza offers choice and facilitates bespoke care centred around the uniqueness of our CYP and their families. This greatly assists the NHS and Local Authorities within our geographical area in meeting and delivering their statutory service obligations. This includes enabling children to be discharged from hospital and admitted to Demelza for end of life care, withdrawal of treatment, symptom management and step down care.

“Demelza also actively works in collaboration with community nursing teams to ensure we reach as many CYP and families that require specialist health support within our region. We support the NHS community nursing teams by being on call 24/7, providing specialist nursing support for CYP requiring end of life care at home. This is prevalent where end of life care is out of hours or over a long period of time where it is not feasible for the NHS to provide this level of support. Demelza provides choice for CYP and families enabling their care to be provided at home or in-hospice, it supports NHS-funded community nursing teams and ultimately prevents admission to hospital.

“Proactive working with statutory service providers to best serve children and families with advance care plans means that Demelza's supporting services help to avoid admission to hospital or family crisis. Ultimately reducing pressure on the NHS and social care systems.

“In addition, social care professionals

will utilise our services when families are in crisis or when safeguarding concerns arise. Demelza is responsive to this un-met need by admitting children and delivering specialist care.

“Demelza is also filling the gap for many children who do not or cannot access statutory respite provision. In the last 12-month period, short break services were provided to 366 children – a 78% increase year-on-year.

“We are actively establishing relationships and working partnerships with ICS within our region to ensure we identify and reach those CYP and families that would benefit from our services and collaborative working arrangements. The services and support we offer is ultimately driven by needs of the families whom we proactively engage with.”

Demelza Hospice Care for Children

“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. In 2022/23, six babies, children and young people (BCYP) were supported to die at home.
- Symptom management to support hospital admission avoidance.
- Step-down care which facilitates earlier discharge from hospital.
- Step-up care where there is a transfer from home to hospice for care to avoid hospital admission.
- Social care placements to support children with social respite provision.
- Crisis respite to support the child and family.

“We have three integrated NHS band six posts that have supported 115 babies, children and young people in 2022/23. These posts support the referral pathway, discharge planning, education and training. These posts have been instrumental in increasing the number of referrals to Haven House in 2022/23.”

Haven House Children’s Hospice

“Children’s palliative care services provide children and young people with the opportunity to have the same experiences as children without palliative care needs. Our environment facilitates the invaluable opportunity to socialise with other children in a safe and supported way. Accessible buildings, grounds and equipment enable children with complex conditions to be children and to have fun in ways that they are often unable to participate. From riding an accessible bike to adapted playground equipment and fun swims. Their symptoms are controlled by familiar staff in a ‘Home from Home’ setting, bringing comfort in their times of need. Dignity and comfort are provided at end of life.

“Siblings who are often young carers attend our services and are given a break from their caring responsibilities. They meet other children who have similar experiences which reduces isolation and improves their overall wellbeing. Siblings who are bereaved have access to specialist, developmentally appropriate support both one a one-to-one basis and in therapeutic groups.

“Parents and carers receive respite from their caring responsibilities, therapeutic support, the opportunity to socialise and peace that their children are cared for. Families receive wrap-around care that spans from a massage to social events, all the way to end of life and bereavement support.

“Services directly reduce hospital admissions and allow for earlier discharges. Indirectly, they impact across the whole system from

social care through to mental health service.”

Havens Hospices

“There is very good collaboration across the region, based on goodwill and the emerging managed clinical network (MCN). Helen & Douglas House is the only provider of specialist medical support to all acute settings including the Oxford University Hospital Trust (tertiary) . This prevents or shortens hospital admissions including stays on Paediatric Intensive Care Unit and Neonatal Intensive Care Unit.

Helen & Douglas House Children’s Hospice

“End of life care, whether in our hospices or at home, reduces inpatient demand in hospital acute settings.”

Hope House Children’s Hospice

“Respite care reduces unplanned hospital admissions for the child. Respite care also reduces demand on the NHS by reducing health crises for the parents/carers. This we know from our own national research with Bournemouth University (Can We Fix It? - Dr Ashley Mitchell) into the impact of respite care, together with York University’s (Fraser et al) longitudinal study of the health of 35,000 mothers.”

Julia’s House Children’s Hospice

“There are huge benefits to the system, including preventing unplanned admissions, providing 24/7 palliative and end of life care in the community (whereas NHS does not provide this out of hours), and facilitating earlier discharges / step-down. More examples can be provided as case studies.”

Keech

“As the only providers of specialist palliative care in the Humberside and North Yorkshire ICB, we have a significant impact on admission avoidance. Without our service the NHS would have to provide this.”

Martin House Children’s Hospice

“We know that through providing end-of-life (EOL), symptom management and emergency and planned respite, we are preventing calls to 111, 999, visits to A+E and hospital admissions. Longer term, we are helping to avoid relationship breakdowns and mental and emotional future health challenges. Some EOL cases come with very difficult social and family relationship circumstances that take a great deal of resources to manage. Child EOL is not predictable and can last a number of weeks (recently three-plus weeks) which include high levels of specialist, medical, nursing, carer and social support. These demands would be difficult to meet in another setting and would demand high local authority and statutory resources to provide. EOL is still not currently being funded by the Hampshire and Isle of White ICB.”

Naomi House & Jacksplace Hospices

“We are very proactive, working with families on an individual basis with assigned social workers. We are therefore able to identify issues at an early stage and therefore offer short breaks before the family reach crisis point. We are integral to the system in terms of end of life responsive care at home and in our facilities and can go over and above what the NHS can afford and provide in terms of wider holistic care for the whole family.”

Noah’s Ark Children’s Hospice

“We have evidence of the impact of the pandemic and cost of living increases on the number of families who are seeking support from us particularly for our counselling, therapy and practical support services.

Requests from families have risen by 25% in the second six months of 22/23. The number of families with complex safeguarding concerns has risen by 20% in 22/23.”

Shooting Star Children’s Hospice

“We facilitate discharges from the acute trust and prevent unplanned admissions through the support we offer to families/carers enabling them to support the child/young person at home. We do this through planned respite both at home and in the hospice.

“We are an active member of the Children’s and Young Person’s Staffordshire Collaborative Project, the aim of which is to enable preferred place of care and death.

“We work alongside the neonatal midwives to support parents. We provide two bedrooms to accommodate children and young people after death. This provision is available to children and young people who are not known to the hospice.”

Douglas Macmillan Hospice

“There is no doubt that we prevent admissions, support early discharge and help families to avoid the impacts of complex grief. We know from our on call services how often we keep families at home and out of hospital, and also support Community Children’s Nurses in the community to do the same.

“The costs of complex grief to families, in the care system and more broadly in society in terms of work and school are substantial, yet we always forget this, despite it being part of the service specification for children.

“We also forget the impact for families as carers, parent carers and young carers of having a child in the home with palliative care needs. This could also be evaluated as part of children’s hospice support.”

Forget Me Not Children’s Hospice

Policy recommendations

52. We recommend the following action to make sure that children's hospice care in England is sustainable for the long-term:

- **Protect, ringfence and increase the NHS England Children's Hospice Grant by the rate of inflation:** we call on ministers and officials to maintain the Children's Hospice Grant as a ringfenced, centrally distributed funding stream from NHS England (NHSE), as is the case now. This will make sure that NHS funding meant for children's hospices reaches children's hospices.
- **Hold integrated boards (ICBs) to account:** the Secretary of State for Health and Social Care should use their new powers in the Health and Care Act 2022 to direct NHSE to make sure that all seriously ill children in England and their families should be able to choose to receive palliative care from children's hospices, if it is in their best interests. This should build on the legal duty on integrated care boards (ICBs) in the Health and Care Act to commission palliative care as they consider appropriate for meeting the reasonable requirements of the people for whom they are responsible.
- **Local and regional action:** ICBs should take our findings into account as they

determine the health and healthcare needs of their populations. ICBs should commission children's hospice and palliative care services in a way which is consistent with their legal duty and the policy framework set out by NHSE⁴ and the National Institute for Health and Care Excellence (NICE).⁵ NHSE should regularly monitor the extent to which ICBs and integrated care partnerships (ICPs) do this through the new strategic clinical networks (SCNs) – and hold them to account if they fail to do so.

- **Government funding for short breaks:** HM Treasury should meet the annual £573 million funding gap in social care for disabled children in England identified by the Disabled Children's Partnership; local authorities could use this funding to make sure that short breaks for respite for families of seriously ill children, including those provided by children's hospices, are sustainable for the long-term.

53. If the UK Government, NHSE and ICBs fail to take this action, seriously ill children and 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.

⁴ NHS England. 2022. Palliative and end of life care: Statutory guidance for integrated care boards (ICBs). Available to download from: <https://www.england.nhs.uk/publication/palliative-and-end-of-life-care-statutory-guidance-for-integrated-care-boards-icbs/>

⁵ National Institute for Health and Care Excellence. 2017. End of life care for infants, children and young people. Quality standard [QS160]. Available to download from: <https://www.nice.org.uk/guidance/qs160>

Children's hospice funding in Northern Ireland

54. The following quote is from Nikki and William Burns, who describe end of life care in Northern Ireland for their son Kaleb:

“If you have to come here (to Northern Ireland Children’s Hospice), it’s the best place to come: it helps to build the family unit again, it helps to build understanding of what the process is like, because when you are going through a palliative process and you are coming to that end stage you don’t know what to expect or how to expect it or how to deal with it, emotionally, mentally or physically. What they did here for Kaleb we are so thankful for...we were a family again.”

The standard of palliative care that children and young people should expect

55. The Northern Ireland Department of Health has published ‘Providing High Quality Palliative Care for Our Children: A Strategy for Children’s Palliative and End-of-Life care 2016-26’⁶. The recommendations were produced by a project group of healthcare professionals, officials and representatives of the Northern Ireland Children’s Hospice.

56. In the strategy, the department stated that each child should have access to 24/7 multi-disciplinary community services and direct access to 24/7 crisis and specialist palliative care advice and end-of-life services, including access to medicines for symptom relief.

Access to 24/7 children’s palliative care across Northern Ireland is a postcode lottery

57. In a progress report in 2021 on work to implement the strategy,⁷ the department stated:

24/7 access to palliative care advice and end of life services is available to children across Northern Ireland. However, much of this is done on an informal basis by clinicians, children’s community nurses and staff from the Northern Ireland Children’s Hospice. Whilst staff work tirelessly to meet the needs of each child, the Paediatric Palliative Care Network recognises that the absence of a formalised commissioned regionally agreed approach is not ideal.

Unsustainable funding

58. Northern Ireland Children’s Hospice has forecast a budget deficit of £1.46 million for 2023/24.

59. This is due in part to a 6% cut in the children’s hospice’s statutory income from the Northern Ireland Health and Social Care system from £2,030,436 in 2022/23 to £1,904,608 in 2023/24.

60. Over the same period, the children’s hospices’ direct costs are forecast to rise by 8% from £3,347,515 in 2022/23 to £3,629,514 in 2023/24

61. If the deficit is not filled by the Northern Ireland Department of Health, it will be forced to cut some of the services it provides to children and families.

⁶ Department of Health. 2016. A Strategy for Children’s Palliative and End-of-Life Care 2016-26. Available to download from: <https://www.health-ni.gov.uk/publications/strategy-childrens-palliative-and-end-life-care-2016-26>

⁷ Department of Health. 2021. A Strategy for Children’s Palliative and End-Of-Life Care 2016-26 Progress Report – June 2021. Available to download from: <https://www.health-ni.gov.uk/sites/default/files/publications/health/doh-hsc-prog-report-childrens-pall-end-life-care-june-2021.pdf>

Action needed to secure sustainable access to hospice care for children and young people in Northern Ireland

62. We ask the UK Government to provide the Northern Ireland Department of Health with the money it needs to fill Northern Ireland Children's Hospice forecast deficit in 2023/24 – and to provide sustainable funding for the long-term.

63. We ask the UK Department of Health and Social Care to facilitate work to share best practice in commissioning and providing children's palliative care between England and Northern Ireland.

64. We also ask the UK Government to make sure that funding which is at least proportionate to that allocated to children's palliative care by the NHS in England, including through the match funding and Children's Hospice Grant funding streams, is allocated to children's palliative care in Northern Ireland.

Children's hospice funding in Scotland

“The death of a child is indescribably devastating and we will always be grateful to the entire CHAS team. I cannot imagine getting through those days, weeks and months without their support and it's heart-breaking that these services are not an option for all that need it within Scotland – yet.” (Parent)

Context

65. Unique in the UK, 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.

66. CHAS supports children and their families with medical, nursing, social work, and emotional and family support.

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

68. For every £1 of statutory funding it receives, CHAS is able to generate £6.24 of public value in return.⁸

69. CHAS has done this for almost 30 years, but demand for its expertise is rising.

70. In the five years since 2014/15, the number of children CHAS has supported has increased by more than 25%, and bed nights for children have seen a 20% increase.

The funding challenge

Funding agreement

71. The 2021/22 Programme for Government commits that the Scottish Government “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.”

72. While this funding is highly welcome, inflationary costs, and the expansion of services to meet demand (including in hospital), have increased CHAS' cost base.

73. Put simply, £7 million per year is no longer sustainable. The majority of CHAS's funding comes from generous donations from supporters, and many families are struggling with the cost of living right now.

Staff costs

74. NHS pay awards – while well-deserved by NHS colleagues - further add to the pressure on CHAS's finances.

75. Hospice staff are not part of the NHS workforce, and in order to attract and retain experienced nursing and medical staff, CHAS must be able to employ on competitive terms.

76. This is not something CHAS can currently match, in a context in which its budget has been set at a deficit of £2.5m for next year.

The 'asks'

77. Funding agreement: CHAS and Together for Short Lives urge the Scottish Government to agree to a new national partnership with the hospice sector – including CHAS – which will enable hospices to continue to support statutory services to meet palliative care need in their communities.

⁸ <https://chas-assets.s3.eu-west-1.amazonaws.com/sites/59dde5b10f7d33796f8cd11b/assets/6042715c0f7d335888887167/YHEC-Executive-Summary-CHAS-Economic-Evaluation.pdf>

78. This will ensure that CHAS does not have to have year-to-year discussions about what level of funding is sustainable to meet the hospice care needs of seriously ill children.

79. **Staff costs:** Urgent funding is needed to mitigate the impact of the recent NHS pay award on the hospice sector. Funding needs to fully cover the wage uplift required to allow hospices to remain equivalent and competitive with the NHS, so nurses aren't forced to take a pay cut to work in a hospice.

About CHAS

80. CHAS' services include:

- **Two hospices:** Rachel House (Kinross) and Robin House (Balloch) that provide respite, palliative and end of life care from CHAS doctors, nurses, pharmacists, physiotherapists and other professionals.
- **Outreach:** CHAS's outreach team operates in every local authority area,

providing highly-skilled nursing care for children in their own homes, as well as a full family support service. This includes social work, income maximisation, bereavement support, transition to adult services for 16 – 21s, and a dedicated activities team.

- **Hospital Teams:** CHAS funds a specialist team in every children's hospital in Scotland, including funding the only specialist medical posts in paediatric palliative care in Scotland. Its nurses provide specialist support alongside the NHS in Glasgow, Edinburgh and Aberdeen.

CHAS' policy vision

CHAS' vision is that all children with life-shortening conditions and their families should have timely access to high quality care, equally across Scotland, when and where they need it. That support should be seamless, and extend from diagnosis through to either bereavement and beyond, or transition to adult services where needed. And that support needs to be sustainably

Children's hospice funding in Wales

81. Much progress has been made implementing the Welsh Government's End of Life Care Delivery Plan⁹ for children, young people and their families. However, the extent to which they can choose to receive palliative care at home, including at the end of their lives, depends on where they live.

82. In 2022, the Welsh Government published a *Quality Statement for Palliative and End of Life Care for Wales*¹⁰. It sets out quality attributes for palliative and end of life care for people of all ages. Among other standards, it states:

- People and their families' preferences for place of care, place of death, and place after death and those factors most important to them are identified, respected, and achieved when possible – that might be short break services for children and young people, care at home (including at care homes), hospital, hospice, the secure estate, or another place of care.
- Children and young people with life-shortening conditions and their families should be able to access 'wrap-around' care that offers therapeutic services which enable them to live their best lives and reach their full potential.
- People's priorities for place of care, such as care closer to home (including care homes) for the growing number of people who will need and want it, will be reflected

in workforce planning and in investment.

83. There is much more to do to make sure that seriously ill children in Wales and their families can access the palliative care they need, when and where they need it. In 2018, the Cross-Party Group for Hospices and Palliative Care in the Senedd published a report¹¹ following its inquiry into the inequalities in access to hospice and palliative care. The report highlighted the shortage of Community Children's Nurses (CCNs) in Wales and the variation in the number and skills. In 2021 we calculated that the current shortfall in CCNs stands at 240.¹²

84. Tŷ Hafan and Tŷ Gobaith have also asked the Welsh Government to re-consider the decision not to pursue the Nurse Associates model currently used in England. These posts in Wales could greatly increase the staffing available to support both the NHS and hospice services, and improve care and would be particularly valuable in the hospice setting, helping to mitigate the ongoing critical shortage in trained paediatric nurses.

85. We joined Tŷ Hafan and Tŷ Gobaith in welcoming the Welsh Government's proposed £888,000 per year increase in funding for Wales's children's hospices. This is the first time additional statutory funding has been made available to Wales's two children's hospices since 2007. The children's hospices will receive

⁹ Welsh Government. 2017. Palliative and end of life care delivery plan – March 2017.

¹⁰ Welsh Government. 2022. Quality Statement for Palliative and End of Life Care for Wales.

¹¹ Welsh Parliament Cross Party Group on Hospices and Palliative Care. 2018. Inquiry: inequalities in access to hospice and palliative care. Available to download from: <https://hukstage-new-bucket.s3.eu-west-2.amazonaws.com/s3fs-public/2022-11/CPG%20Hospices%20and%20Palliative%20Care%20inquiry.pdf>

¹² Together for Short Lives. 2021. Policy priorities for the next Welsh Government. Available to download from: <https://www.togetherforshortlives.org.uk/app/uploads/2021/04/210412-TfSL-Policy-priorities-for-the-next-Welsh-Government.pdf>

around 21% of the costs of providing palliative care to children and families in Wales.

This was the first time additional statutory funding has been made available to Wales's two children's hospices since 2007. It is an important step in building towards a sustainable future for the two hospices and will allow 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.

Together for Short Lives, Tŷ Hafan and Tŷ Gobaith are concerned that the second phase of the Welsh Government's hospice funding has not resulted in any additional funding to enable the children's hospices to sustainably provide community-based hospice and palliative care.

We ask that the Welsh Government:

1. Provide additional money to make sure Tŷ Hafan and Tŷ Gobaith are sustainably funded in the long-term.
2. Takes steps to ensure that all children in Wales who need palliative care, including babies, can access community children's nurses 24/7. These services can be provided by NHS children's community nursing teams, hospice at home teams, hospital outreach teams, or a combination. To do this, these services would need to be sustainably planned and funded by local health boards.
3. Act to make sure that there are enough children's nurses with the skills, knowledge and experience needed to provide palliative care to children in the community.
4. Re-consider the decision not to pursue the Nurse Associates model currently used in England.