

JUNE 2022



CHILDREN'S HOSPICE FUNDING IN 2021/2022

A REPORT FROM
TOGETHER FOR SHORT LIVES



Introduction

In April and May 2022, Together for Short Lives asked children's hospices across the UK how they were funded in 2021/22. 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 2022/23.

22 of the UK's 37 children's hospice organisations responded to our survey. All provide children's hospice and palliative care to children and young people in England. This report summarises their responses and sets out the action we call on the UK Government and NHS England and NHS Improvement (NHSE/I) 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.

Executive summary

- Our survey shows a wide variation in local NHS funding for children's hospices in England. Lifeline hospice care for seriously ill children and young people could be put at risk if NHS England do not commit to providing the Children's Hospice Grant as a central grant beyond 2023/24.
- Important progress has been made in NHS funding for children's hospices in recent years. The government and then NHS England have provided a central grant to children's hospices since 2007, which in 2021/22 was worth a total of £17million. On average, it represented around one pound in every six of spent by children's hospices on the care and support they provide (15%).
- The grant is a vital funding source amid a patchy funding for children's hospices from local NHS organisations (clinical commissioning groups, or CCGs) and local authorities. While average funding from CCGs represented one pound in every five spent by children's hospices in 2021/22 on the care and support they provided (an average of £689,000 for each children's hospice from CCGs, an increase of 38% compared to 2020/21), the amounts received by individual children's hospices varied greatly: half of children's hospices (50%) saw their CCG funding decrease between 2020/21 and 2021/22. Nearly one in ten (9%) children's hospices received over half of their charitable expenditure from CCGs, while one in five (22%) received five per cent or less of their charitable expenditure from CCGs.
- Across the range of types of care and support, a majority of children's hospices are either expanding or maintaining them at current levels. However, it is concerning that over a quarter (27%) of children's hospice are cutting short breaks for respite as a result of funding changes between 2020/21 and 2021/22. As set out in paragraph 30, despite average increases in overall income, the high rate of vacant care professional posts is restricting many children's hospices' ability to expand their services for seriously ill children and young people.
- On average, children's hospices' active caseloads have increased by 11% from 262 in 2020/21 to 292 in 2022/23. This is 6% greater on average than the 276 reported in 2019/20. Children's hospices report greater levels of activity across most of the types of care and support they provide. On average, children's hospices provided end of life care to 54% more children (20 per children's hospice, compared to 13 in 2020/21 and 11 in 2019/20), symptom management to 50% more children (37 per children's hospice compared to 25 in 2020/21 and 18 in 2019/20) and short breaks for respite to 27% more children (123 per children's hospice compared to 97 in 2020/21).
- However, overall, some types of activity are still at levels lower than before the pandemic, including short breaks for respite (17% down in 2021/22, compared to the average of 148 children per children's hospice who received them in 2019/20) and hospice at home (31% down in 2021/22, compared to the average of 102 children per children's hospice who received this care in 2019/20).
- Together for Short Lives welcomes the planned increase in the NHS England (NHSE) grant to £21million in 2022/23 and then £25million in 2023/24. While the rise is very welcome, officials are refusing to commit to protecting and extending the grant as funding stream distributed centrally by NHS England after 2023/24. Children's hospices are already warning that if they were unable to access the grant in 2024/25 and beyond, they would be forced to cut vital care and support for children and families:

- nearly one in five (18%) would cut end of life care
 - over a quarter (27%) would cut symptom management services
 - nearly two thirds (64%) would cut short breaks for respite.
- Children’s hospices provide vital care and support to seriously ill children and their families. They offer lifeline physical, emotional and spiritual support and help children and families to make meaningful choices about care in hospices and at home. In doing so, they take pressure away from overstretched hospital services.
 - Children’s hospices need sustainable funding from the NHS, local authorities and charitable sources to meet the needs of a growing population of seriously ill children and young people who have an increasingly complex range of needs. Together for Short Lives welcomes the progress that the government and NHS England have made on children’s hospice funding in recent years. The increase in the Children’s Hospice Grant, coupled with the NHS Long Term Plan match funding for children’s palliative care, mean that, on average, children’s hospices are accessing higher levels of statutory funding.
 - On average, children’s hospices expect their charitable expenditure to grow by over one fifth (22%) between 2021/22 and 2022/23. 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 hospices charities in England was over 18%. Like other employers, children’s hospices face growing costs as inflation soars and they compete to recruit and retain staff. They now rely on the larger Children’s Hospice Grant to help them meet their growing costs.
 - We recommend 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 and extend the NHS England Children’s Hospice Grant:** with patchy local NHS funding and the negative experience that some children’s hospices have reported in trying to access the NHS Long Term Plan match funding and £25million non-recurring funding in 2019/20, we call on ministers and officials to maintain the Children’s Hospice Grant as a ringfenced, centrally distributed funding stream from NHS England. This will make sure that NHS funding meant for children’s hospices reaches children’s hospices.
 2. **Hold the new integrated care systems (ICSs) to account:** the Secretary of State for Health and Social Care to use their new powers in the Health and Care Act 2022 to direct NHSE/I 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:** as ICSs operate on a statutory footing from July, integrated care partnerships (ICPs) should take our findings into account as they determine the health and healthcare needs of their population. Integrated care boards (ICBs) should commission children’s hospice and palliative care services in a way which meets the NICE standards. NHSE should regularly monitor the extent to

which ICPs and ICBs do this through the new 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 government, NHSE and ICSs 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.

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Case study: Isla and the lifeline care that children's hospices like ellenor provide

Finally getting the correct diagnosis and treatment is key to helping families get on with their lives, which is why, for one mum, discovering what was wrong with her daughter was in some ways “a relief”. Now – with support from ellenor – the family is finding day-to-day living manageable again.

“When you know something is wrong with your child but not exactly what, it's very frightening – it's the stage when you feel things are spiralling out of control. Getting a diagnosis for Isla was a relief in some ways because suddenly all her symptoms made sense. And, of course, once you've got a diagnosis, you can start working on a treatment plan.”

So says Gemma Stanley, mum of four-year-old Isla, who was referred to ellenor by the Royal Marsden hospital back in August.

Isla was born with Gorlin syndrome, which leaves her with an increased risk of developing cancer. At just three months old, she was regularly having episodes during which she stopped breathing – a terrifying time for her parents. After weeks of investigations, she was rushed to the Evelina hospital in London and given a tracheostomy within hours of her admission. Gemma stayed with her for the five-month treatment and recovery process: “You're not discharged with your child until they're well enough to cope physically, and you as their parent are able to cope in practical terms with the tracheostomy,” she explains. “I needed to be able to change the various tubes and, once she was at home, we had carers during the night so that someone was always wide awake whenever Isla needed care.”

Two and half years later, Isla was breathing independently, with the tracheostomy tube removed in the summer of 2018. In many ways, life seemed back to normal for the family – Isla was fit and happy and thriving at mainstream nursery, while Gemma and partner Ashley had decided the time was right to try for another baby. Scroll on to February 2020 and Gemma was pregnant, but Isla was clearly unwell. This was the point at which Gemma thought things were on the verge of unravelling all over again: “The doctors were trying Isla on antibiotics because she was lethargic, vomiting and not eating. Then, I found a hard lump in her stomach.” A biopsy at the Royal Marsden revealed a cancerous tumour on her kidney, with an immediate and intensive 27 weeks of chemo following its removal. To say it was a full-on time is an understatement. By July, however, the ellenor team were involved in Isla's care.

“We were referred to ellenor via the Marsden, so that we could have help at home,” explains Gemma. “I'm a local girl and it's always been ‘our’ hospice – my nan died in their excellent care and subsequently as a family we've always supported ellenor's Christmas fundraising activities and friends who've done ellenor's Twilight walk. I was really surprised, though, to learn that the charity offers so much holistic support for people who are more preoccupied with living than dying. It's not possible under the current circumstances, but we know that ellenor has also offered fantastic support in terms of holidays for families, and group days out – something they'll continue to do once restrictions are lifted.”



“We have a team of nurses who come in weekly to check Isla’s bloods and change her ‘wiggly’ – the name we have for her portacath - and it’s just brilliant: it’s one less hospital visit for us, and Isla is so relaxed with the team that she just watches TV while they do what they need to do. The nurses will also make sure I have all the equipment and medication I need – back in the days when I was dealing with the tracheostomy, I had to order some of the supplies myself.”

Gemma says that the ellenor team’s weekly presence – and constant availability at the end of the phone – has made life so much easier for her and Ashley, not only as Isla’s parents but as mum and dad to Brooke, too, who was born back in September. “It’s been a very full-on time,” says Gemma in what sounds like something of an understatement. “But we’re getting on with life as a family and Isla’s very good with Brooke – no sign of the sort of jealousy you sometimes see when a new baby comes on the scene!

“We’re so proud of Isla – she’s cheeky, funny and strong. While Covid hasn’t made things any easier, you can feel isolated even under normal circumstances as a parent with a sick child. The fact that now we all feel isolated is something of a leveller. We’re so grateful to have a whole team of people supporting us – family, friends, medical experts – and the brilliant team at ellenor is a key part of the network that’s helping us get on with our lives.”

Our detailed findings

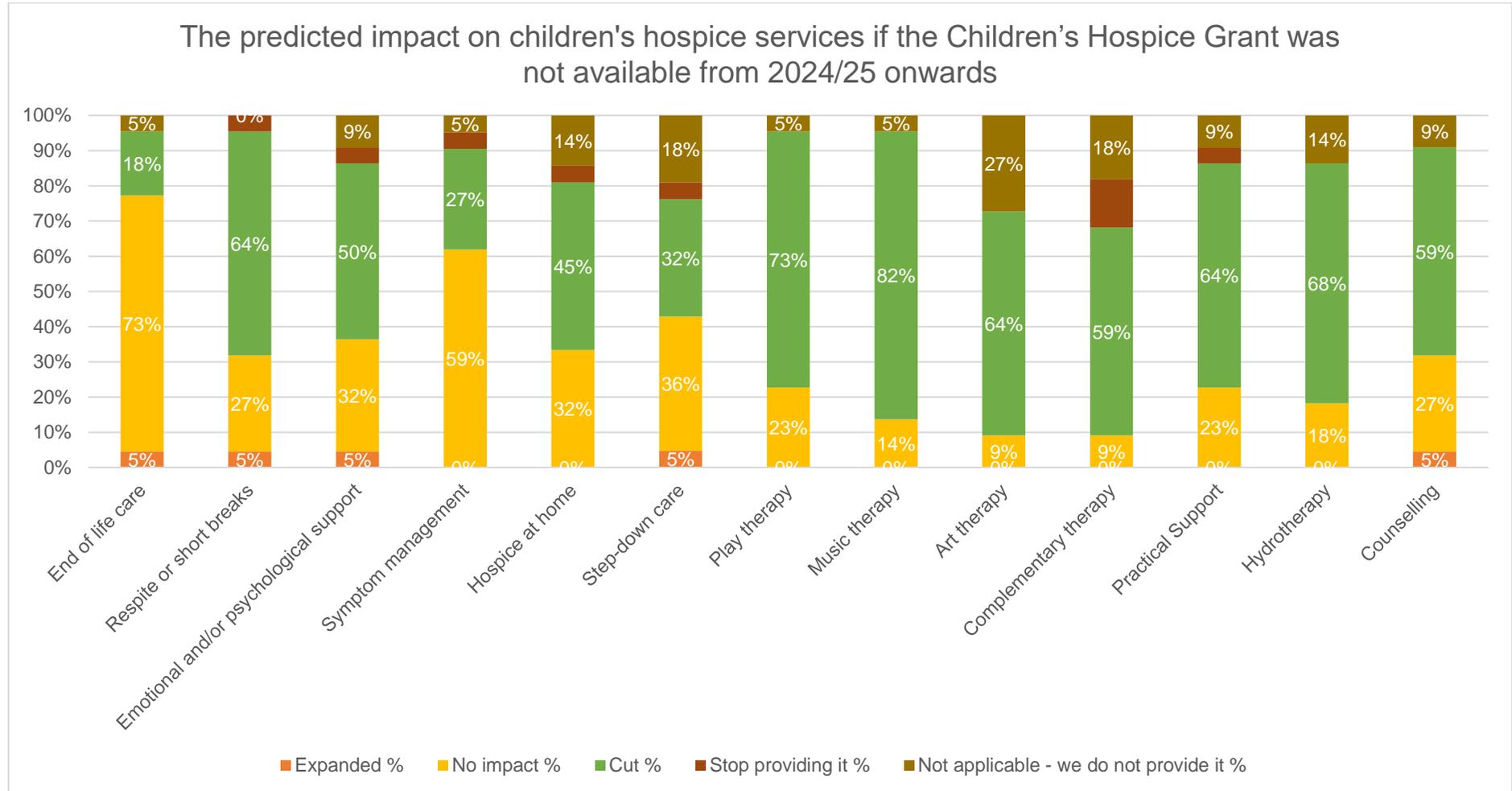
The NHSE/I Children and Young People's Hospice Grant

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 are:
 - 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 ICSs 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, believe that devolving all NHS children's hospice funding to ICSs could exacerbate the current inequity in funding: seriously ill children represent a small but complex population compared to other groups that ICSs need to plan and fund services for. As a result, in many cases, CCGs have not prioritised work to commission children's palliative care. This has been the case even when funding has been available for CCGs from government and NHSE, such as the NHS Long Term Plan children's palliative care match funding, which not all CCGs 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 as a 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. 15 (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. 10 of the 11 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. Of the 22 children's hospices that answered this question, a majority would cut all of their services apart from end of life care, symptom management and step-down care. However, within this:

- nearly one in five (18%) would still cut end of life care
- over a quarter (27%) would still cut symptom management services

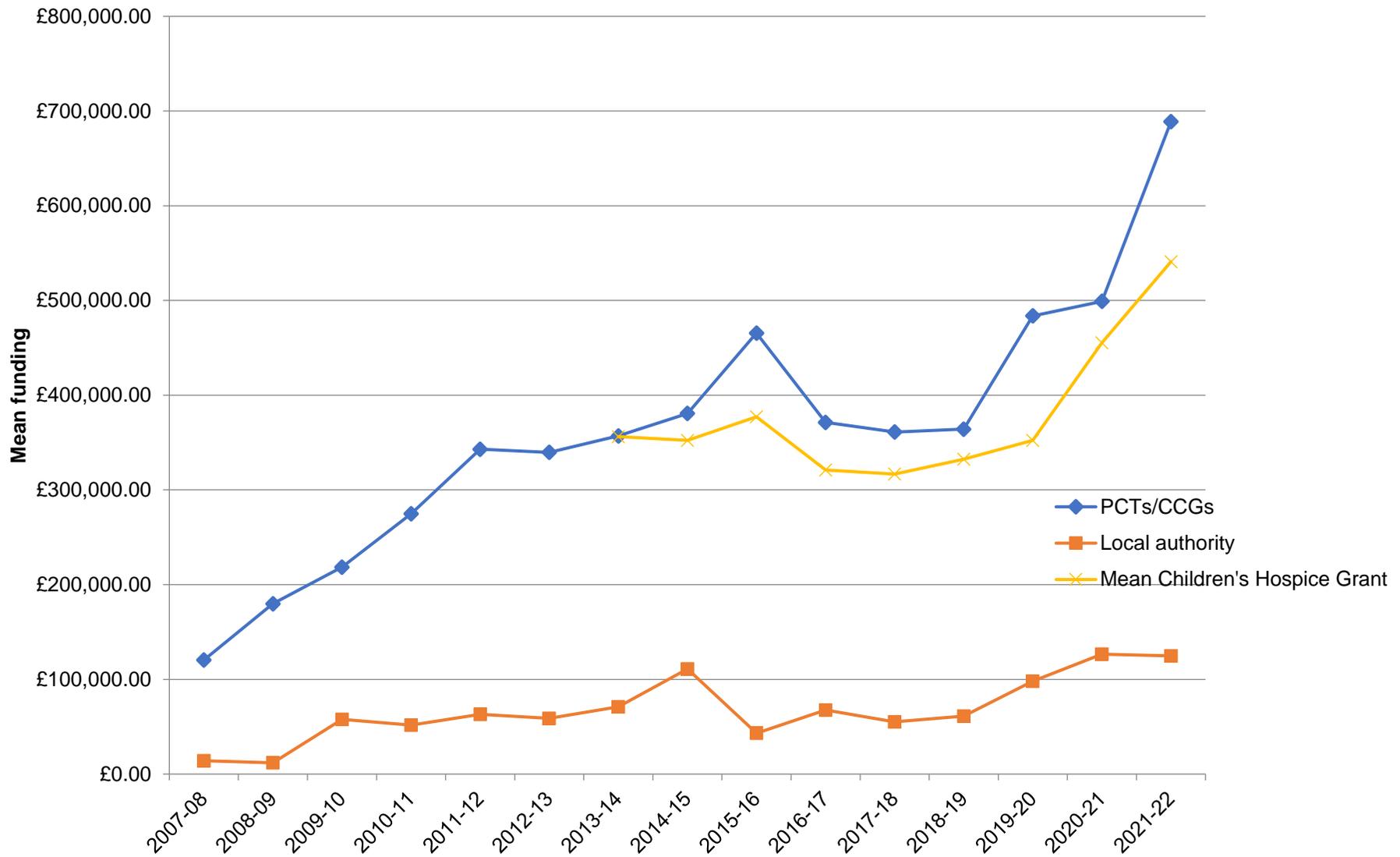
9. Worryingly, nearly two thirds (64%) would cut lifeline short breaks for respite for seriously ill children and families.



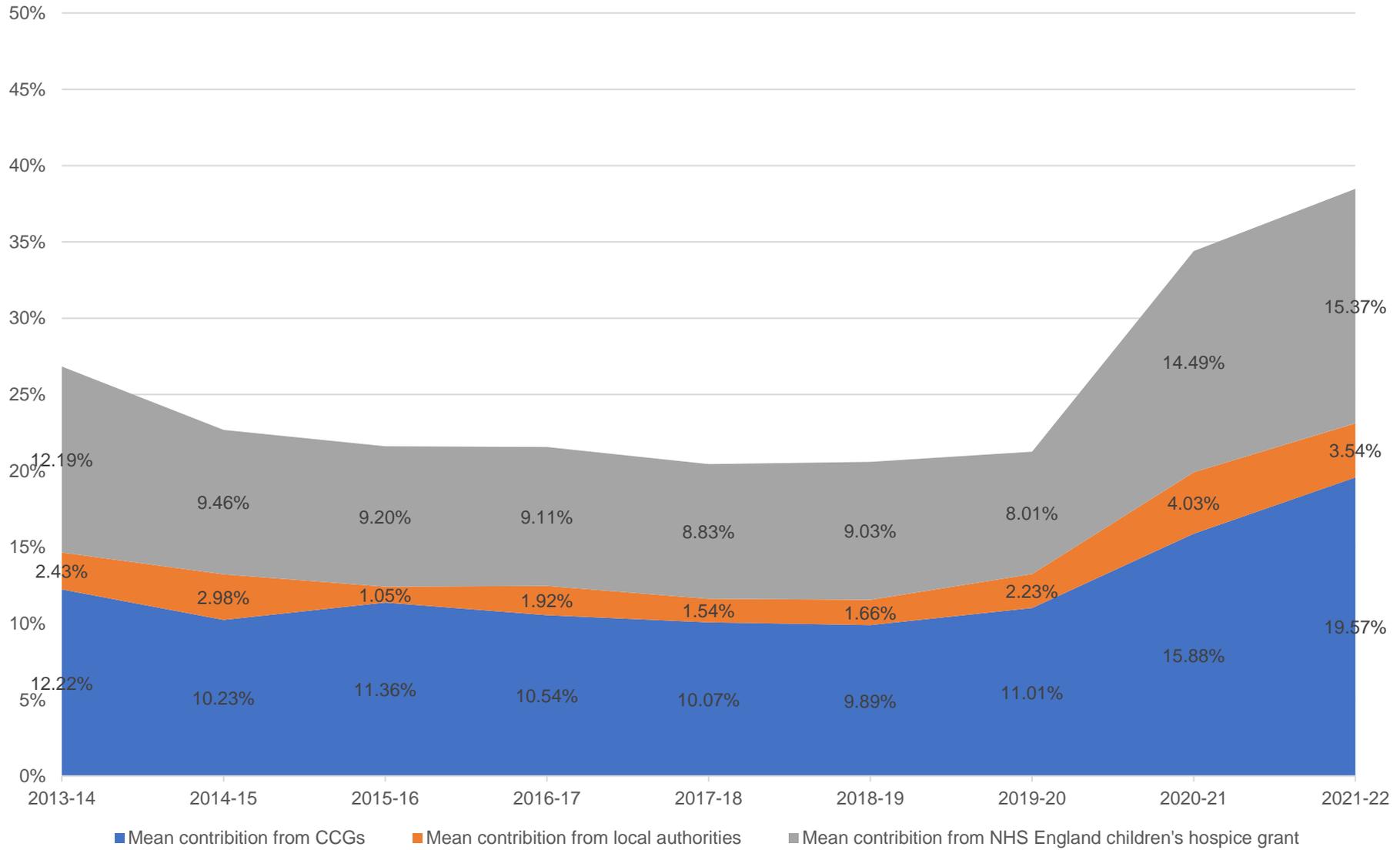
Local NHS funding in England

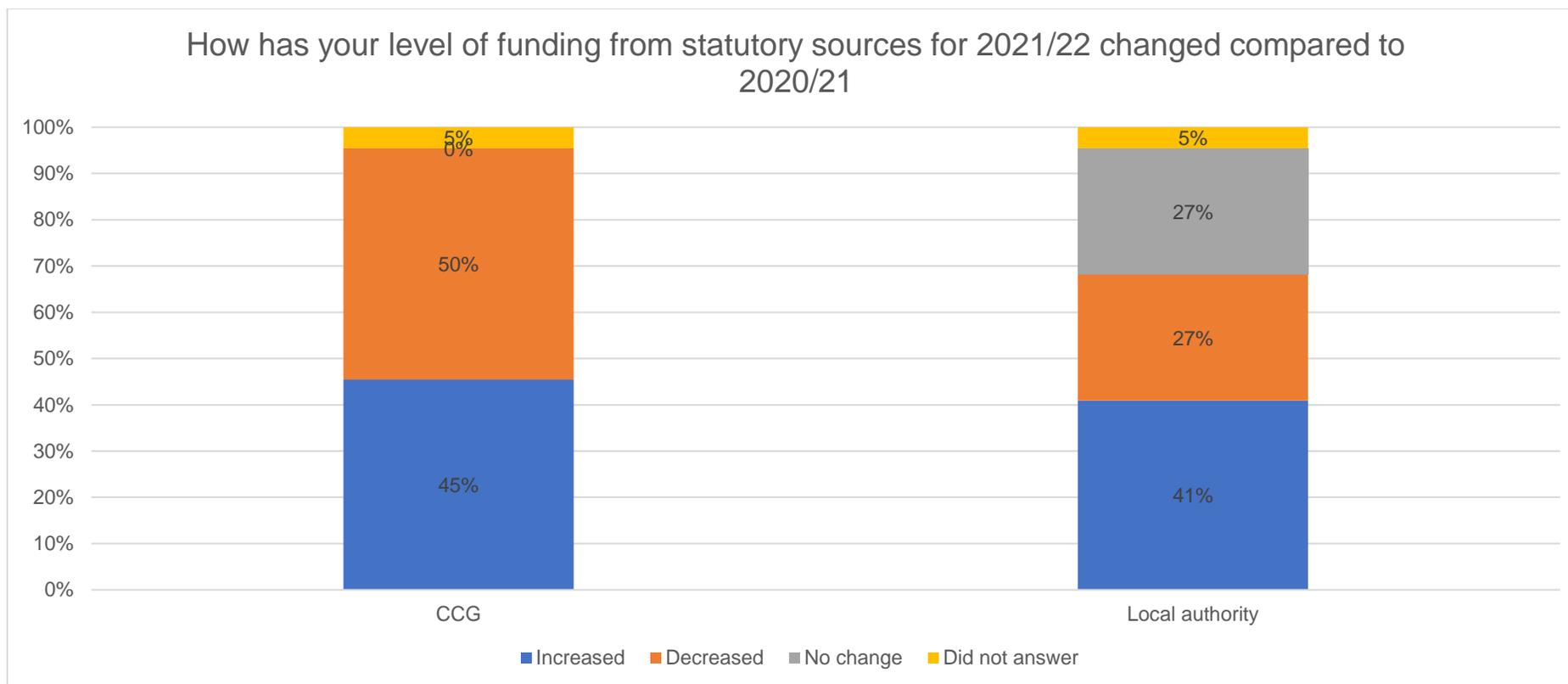
10. The NHS Long Term Plan commits NHSE/I to match up to £7million of CCG funding for children's palliative care, including children's hospice services, by 2023/24. The money is available to NHS and voluntary sector providers and is already being used to fund children's hospice and palliative care services. The funding amounts during this period are:
- 2020/21: £2million
 - 2021/22: £3million
 - 2022/23: £5million
 - 2023/24: £7million.
11. This increase in funding available to local NHS organisations could be one of the factors contributing to the average increase in CCG funding for children's hospices in England. On average, children's hospices received £688,829.70 from CCGs in 2021/22, a 38% increase compared to the £499,025.72 they received in 2020/21. This represented one fifth (20%) of their charitable expenditure, up from the 16% that CCG funded in 2020/21.
12. Despite this overall increase, however, CCG funding for individual children's hospices varies significantly at local level:
- 11, equal to half (50%) of children's hospices, saw their CCG funding decrease between 2020/21 and 2021/22. 10 (45%) received greater CCG funding.
 - Nearly one in ten (9%) children's hospices received over half of their charitable expenditure from CCGs, while one in five (22%) received five per cent or less of their charitable expenditure from CCGs.
13. Children's hospices expected their average funding from CCGs to increase by 8% to £741,624.57 in 2022/23. 12, over half (54%) of children's hospices, expected their CCG funding to increase, compared to eight (36%) who expected it to decrease. One children's hospice (5%) expected no change in their CCG funding. One children's hospice did not provide us with their predicted CCG funding figure for 2022/23.

Mean local funding for voluntary sector providers of children's palliative care 2007 - 22



Proportion of voluntary sector children's palliative care providers' charitable costs reimbursed by the state 2014-22





Local authority funding in England

14. Of the 22 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 £ £124,783.84 each. This represented a 1.4% fall on the £126,587.65 reported in 2020/21 and represents a small proportion (3.4 per cent) of the charitable costs incurred by children’s hospices in 2021/22. 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.

15. Despite the average increase in local authority funding across England, funding varies widely between children’s hospices. Six children’s hospices (27 per cent) reported a cut in local authority funding between 2020/21 and 2021/22. Nine (41%) reported an increase. Six (27 per

cent) reported that their local authority funding did not change. This means that over half (52 per cent) of children's hospices reported a cut or freeze in their local authority funding between 2020/21 and 2021/22.

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

"The continued Match funding from NHSE/I has helped us to increase our family team resource. We still do not feel we have equitable funding from the local authorities in comparison to CCGs."

Acorns Children's Hospice

"The current Children's Hospice Grant funding works well. Funding via CCGs is much more difficult to achieve and time consuming using valuable staff resources."

Alexander Devine Children's Cancer Trust

"Grant agreements rather than activity based has ensured we receive regular funding."

Bluebell Wood Childrens Hospice

"It is crucial that hospices are funded fairly and sustainably for the services they provide for babies, children, young people and their families. There are several issues which mean this is not the case. Failure to fund core services: the recently published Service Specification and Investment Framework should mean that services are appropriately commissioned. However, CCGs continue to rely on our hospice to use voluntary income to ensure the hospice is available 24/7 throughout the year, so that the CCG can spot-purchase as and when a child from their area requires palliative care. The CCG pays for only those nights when the child is resident at the hospice, which means the hospice takes the full risk of absorbing the costs if a child is admitted and receives our care but the CCG refuses to pay. The nightly rate is subsidised by the hospice and there is an inequitable relationship regarding payment and contribution towards this core service. Lack of integration: many CCGs and Local Authorities continue to work separately, resulting in unsuitable or inequitable funding arrangements. For example, our recent funding application to a Local Authority short breaks service to provide short breaks in the child's home was turned down because nurses and health care professionals would be providing the service. This would mean safe care for the children, but was deemed to be the CCGs responsibility. The Local Authority's short breaks units are not able to cater for the complex health needs of some children, but the CCG does not fund alternatives. It is hoped that the recent changes in the Health and Social Care bill requiring the NHS to fund palliative care will have a beneficial impact on funding and on collaborative relationships between the statutory and voluntary sector."

Demelza Hospice Care for Children

“ellenor prides itself in supporting children and families throughout the many challenges they face, working in partnership with other providers to do so. All children and families facing a life limiting condition should have choices as well as access to the same level of care and support regardless of where they live and ellenor supports the drive to ensure this becomes a reality.”

ellenor

“We would be looking at 35% of charitable costs to be commensurate with adult hospices. Funding should be representative of all areas we cover geographically. We should not be paying for drugs or pharmacy support. We should not be paying a margin on any Doctor/staff costs bought in from the NHS. We are increasingly being commissioned for funded placements rather than being paid under spot purchase arrangements. This helps with planning. We are seeking a sustainable 3 year partnership arrangement with LA's around our SUDIC service.”

Forget Me Not Children's Hospice

“We work extremely closely with our local CCGs and have developed a good working relationship. We have secured our cost and volume contracts for 2022/23 and have worked with our CCGs to uplift the tariff and include a low and high complexity tariff. We have secured an NHS grant agreement with two CCG areas in a local ICB.”

Haven House Children's Hospice

“No funding is received from local authorities and there is no understanding that they have an obligation to provide short breaks...less than inflation increases from CCGs will reduce statutory income in 2022/23.”

Hope House Children's Hospices

“We agreed an SLA payment with local authorities in 2008. This payment has not increased or been reviewed since 2008 despite us now offering overnight respite, a significant increase in children we support and the respite hours now offered.”

James Hopkins Trust

“Our current statutory funding provides a very small percentage of our overall costs, the rest we have to rely on fundraising activity, but yet we provide a full range of services.”

Rainbows Hospice for Children and Young People

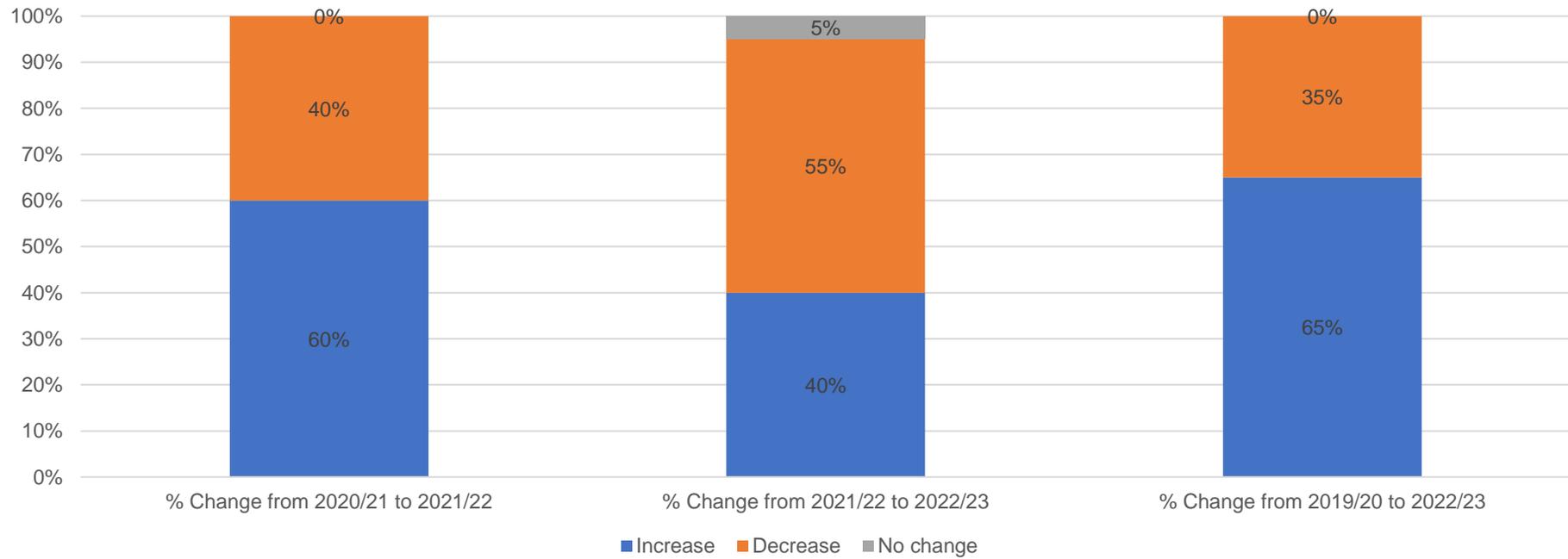
“During 2021/22 we received significant one-off legacy income and COVID funding, neither of which will be repeated in coming year 2022/23. However we have negotiated with local authorities to fund 65% of cost of service which is a substantial increase on two years ago and provides stability in such uncertain times.”

St Oswald's Hospice

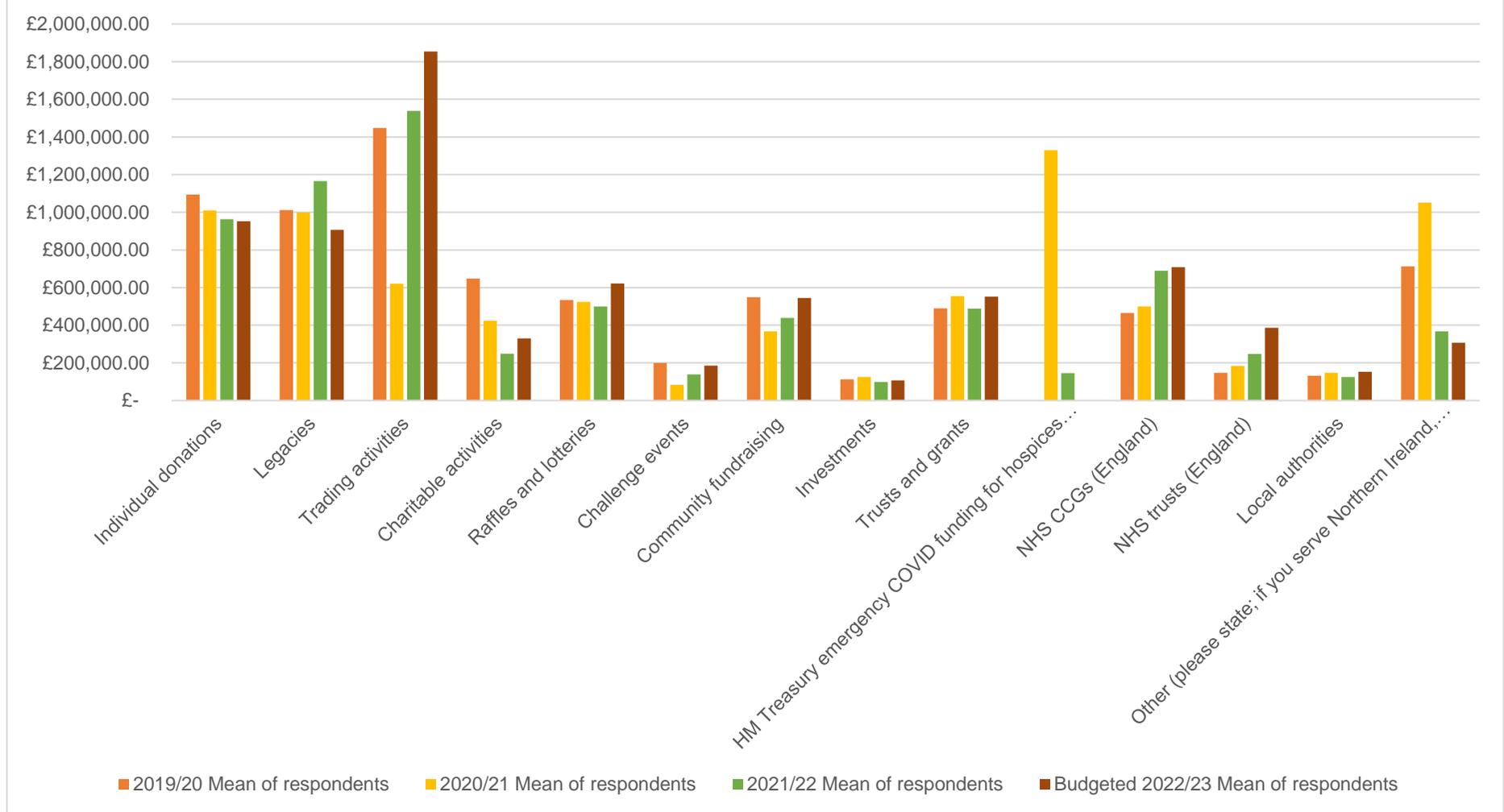
Income

16. Among the 21 children's hospices who told us about their total income in 2021/22, their average income was £7,183,888.10, a 2% increase on the average of £6,954,324.79 received in 2020/21.
17. Income varied between children's hospices, however. 12 (60%) of children's hospices reported that their income increased between 2020/21 and 2021/22. 40% (8) reported a reduction.
18. On average, children's hospices expect their total income to fall by 1% to £7,122,407.67 in 2022/23.
19. Predicted income also varies between children's hospices. 8 (40%) of children's hospices expect their income to increase between 2021/22 and 2022/23. 55% (11) expect a reduction and one (5%) predicts no change.

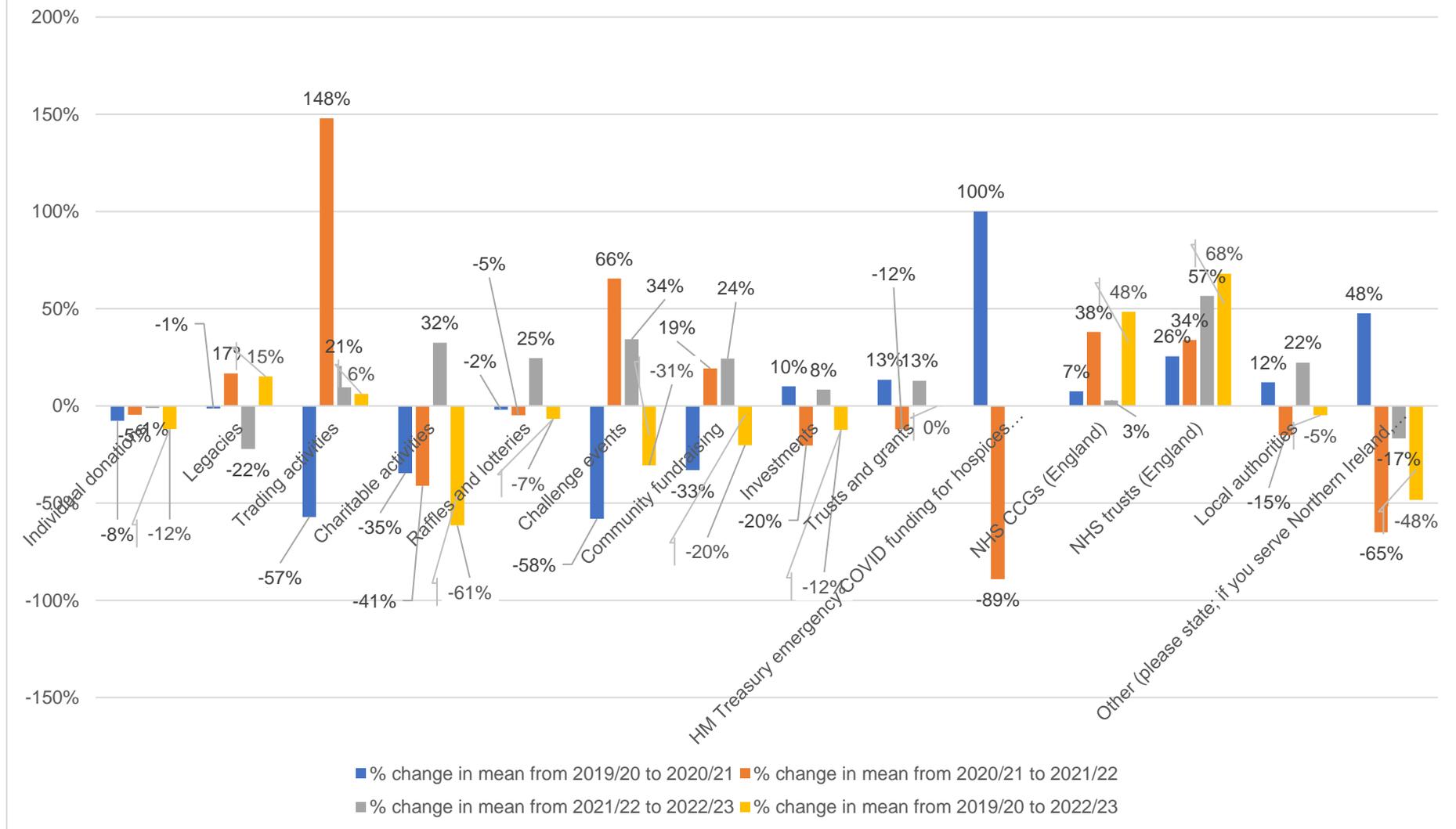
Change in children's hospices income 2019-2023



Mean children's hospice income by source 2019-2023



% change in mean children's hospice income by source 2019-2023

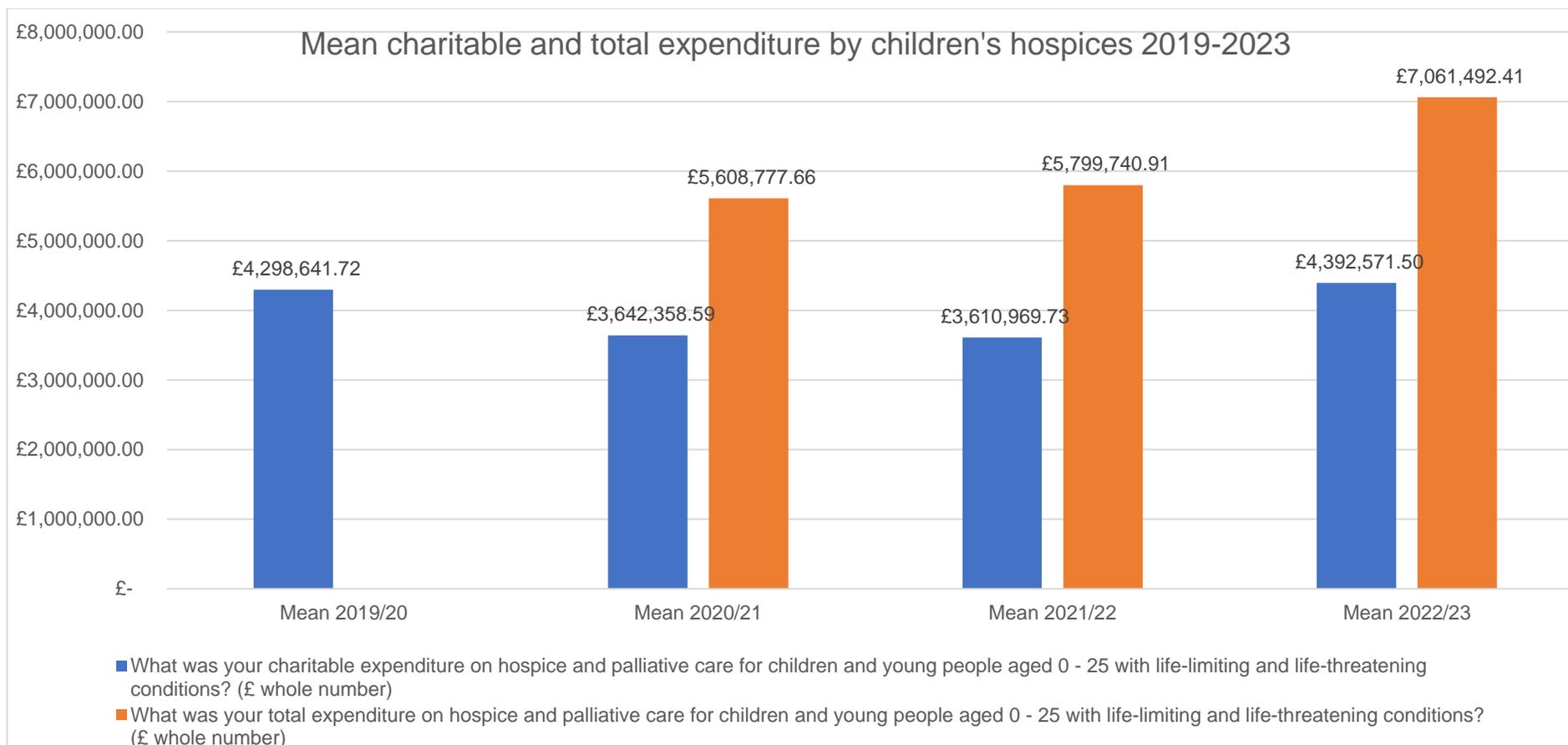


Income by source

20. As COVID restrictions eased, these increases were driven by trading activity, which grew on average by 148% from £620,436.50 in 2020/21 to £1,538,234.57 in 2021/22. This source represented a fifth (21%) of children's hospices' income on average, compared to 9% in 2020/21. Children's hospices expect their trading activities to increase again on average by 6% in 2022/23.
21. Average legacy payments also grew by 17% from £998,927.14 in 2020/21 to £1,165,308.14 in 2021/22. They represented 17% of children's hospices average income in 2021/22.
22. Worryingly, however, average individual donations to children's hospices fell by 5% from £1,009,733.86 in 2020/21 to £963,348.95 in 2021/22, when they represented 13% of children's hospices' income.
23. In April 2020, the government's Emergency Coronavirus Fund for charities included a commitment of £200million for hospices, including children's hospices. In November 2020, the government announced that it would provide an additional £205million of support for the NHS for the winter 2020/21. This included up to £125million to secure additional hospice capacity and up to £148million for the period December 2021-March 2022 to secure and increase NHS capacity to enable hospital discharge.
24. The average fall in income predicted by children's hospices in 2022/23 is driven in part by an expected reduction in income from legacies, which children's hospices expect to fall 22% to an average of £906,671.95 in 2022/23.

Charitable expenditure

25. On average, children's hospices reported that their charitable expenditure fell slightly by 1% from £3,642,358.59 in 2020/21 to £3,610,969.73 in 2022/23.
26. However, on average, children's hospices expect their charitable expenditure to grow by over one fifth (22%) between 2021/22 and 2022/23. 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 hospices charities in England was over 18%. Like other employers, children's hospices face growing costs as inflation soars and they compete to recruit and retain staff. They now rely on the larger Children's Hospice Grant to help them meet their growing costs.

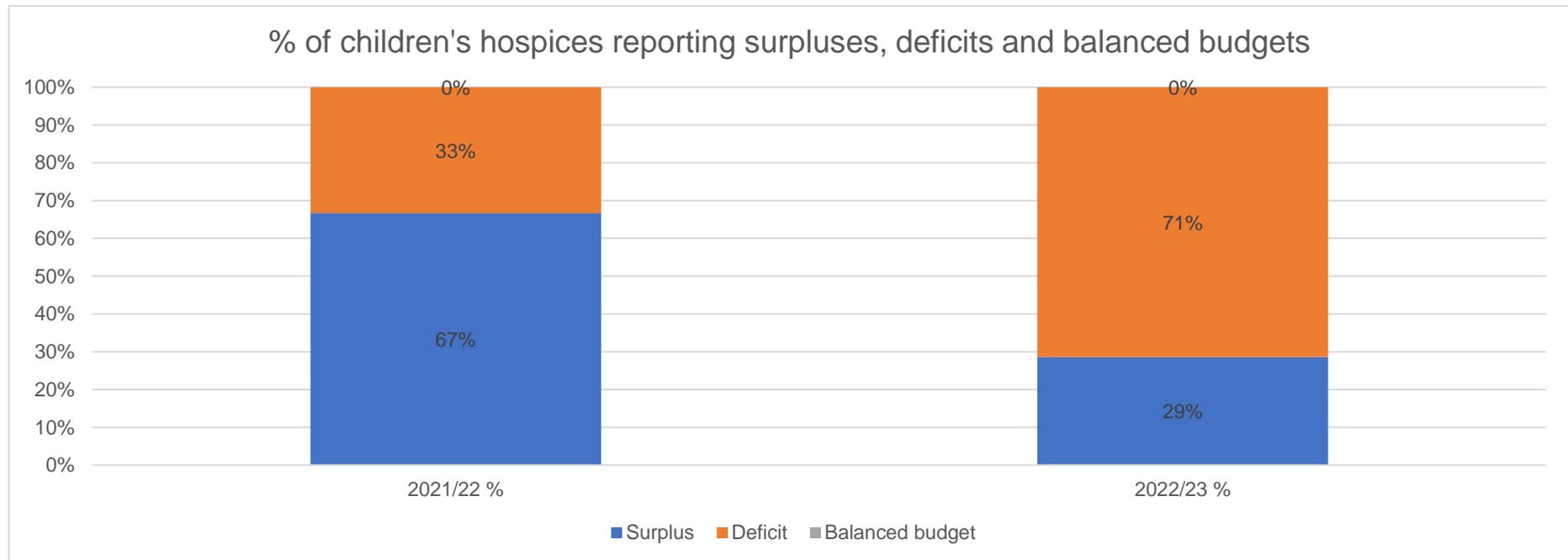


Total expenditure

27. Children's hospices total expenditure, which includes fundraising costs, rose on average by 3% from £5,608,777.66 in 2020/21 to £5,799,740.91 in 2021/22. On average, they expect it to rise again by 22% to £7,061,492.41 in 2022/23.

Balance between total income and total expenditure

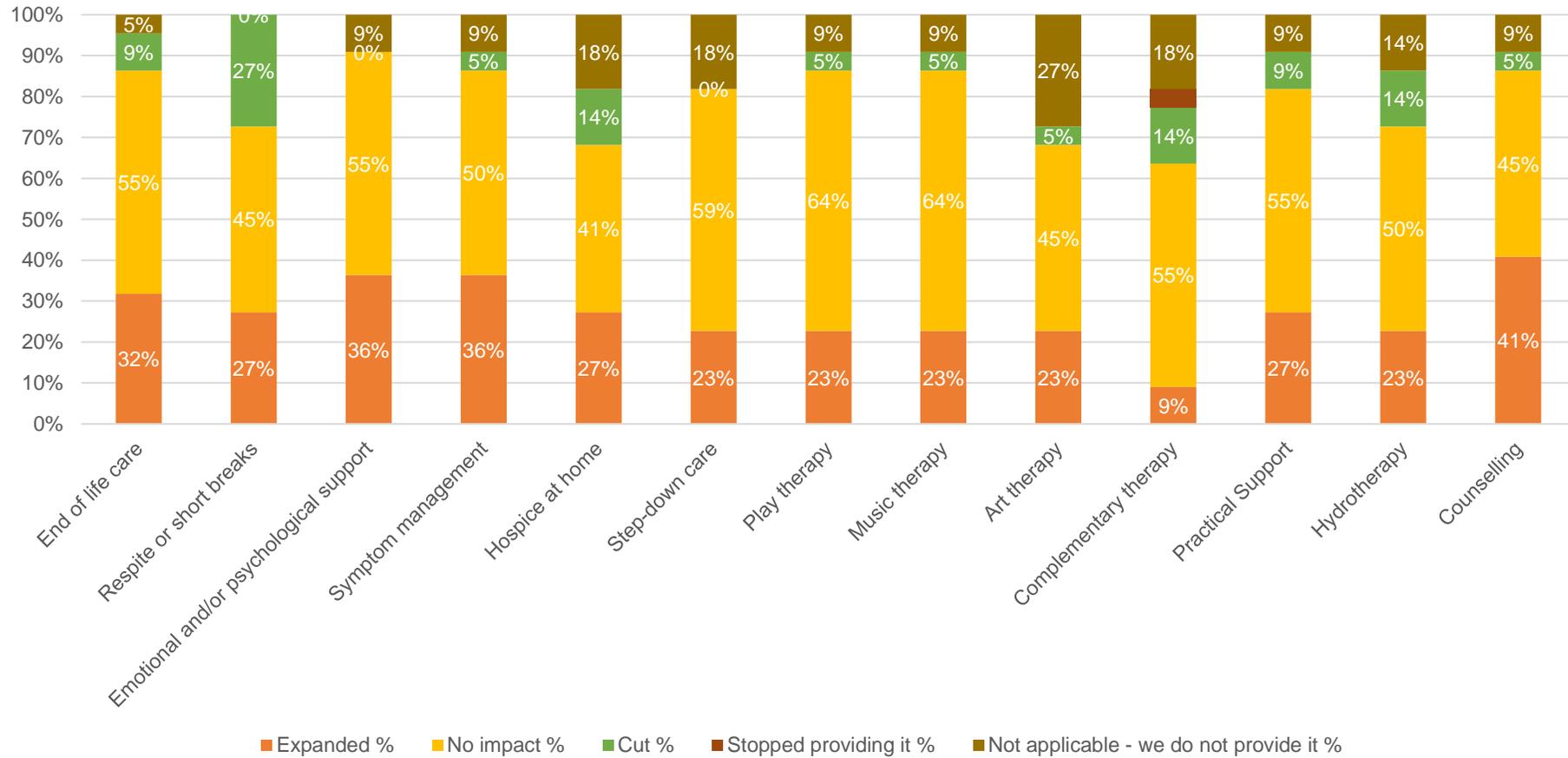
28. Overall, 14, equal to two thirds (67%) of children's hospices reported a net surplus in 2021/22. Seven, representing a third (33%) of children's hospices, reported a net deficit.
29. However, 15, representing over two thirds (71%) of children's hospices, predict that they will experience a net deficit in 2022/23. Just six (29%) expect to make a surplus.
30. Taking all respondents' surpluses and deficits into account, and on average, children's hospices made a surplus of £1,118,992 per children's hospice in 2021/22. However, in 2022/23, on average, children's hospices expect to report a deficit of £259,132 per children's hospice. Extrapolated across all 34 children's hospice organisations in England, this would represent a shortfall of £8,810,496.



Impact of funding changes on services

31. Across the range of types of care and support, a majority of children's hospices are either expanding or maintaining them at current levels. However, it is concerning that over a quarter (27%) of children's hospice are cutting short breaks for respite as a result of funding changes between 2020/21 and 2021/22. As set out in paragraph 30, despite average increases in overall income, the high rate of vacant care professional posts is restricting many children's hospices' ability to expand their services for seriously ill children and young people.

Impact that changes in funding between 2020/21 and 2021/22 have had on the services provided by children's hospices



“Low staffing means we are unable to offer additional statutory funded care to our families as this would impact on the provision of our charitable funded care. This means the CCG/LA payments are no longer being made and the uplift in those payments supported our charitable funded care.”

James Hopkins Trust

“We have been able to reach more children young people and families across the East Midlands.”

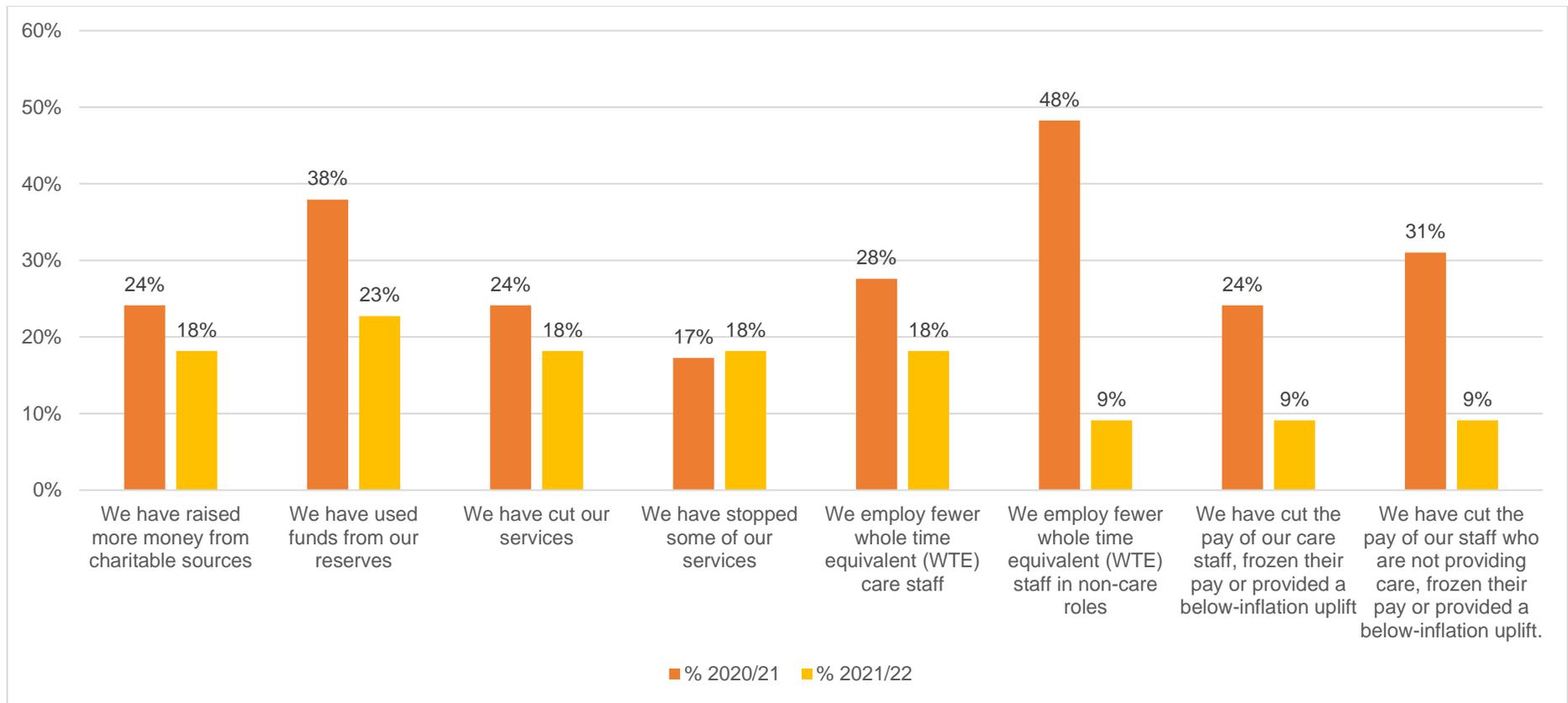
Rainbows Hospice for Children and Young People

“Increase in capacity has been positive however we still have a significant waiting list of children and young adults meeting our criteria, who still can't access the service.”

St Oswald's Hospice

Mitigating the impact of changes in funding

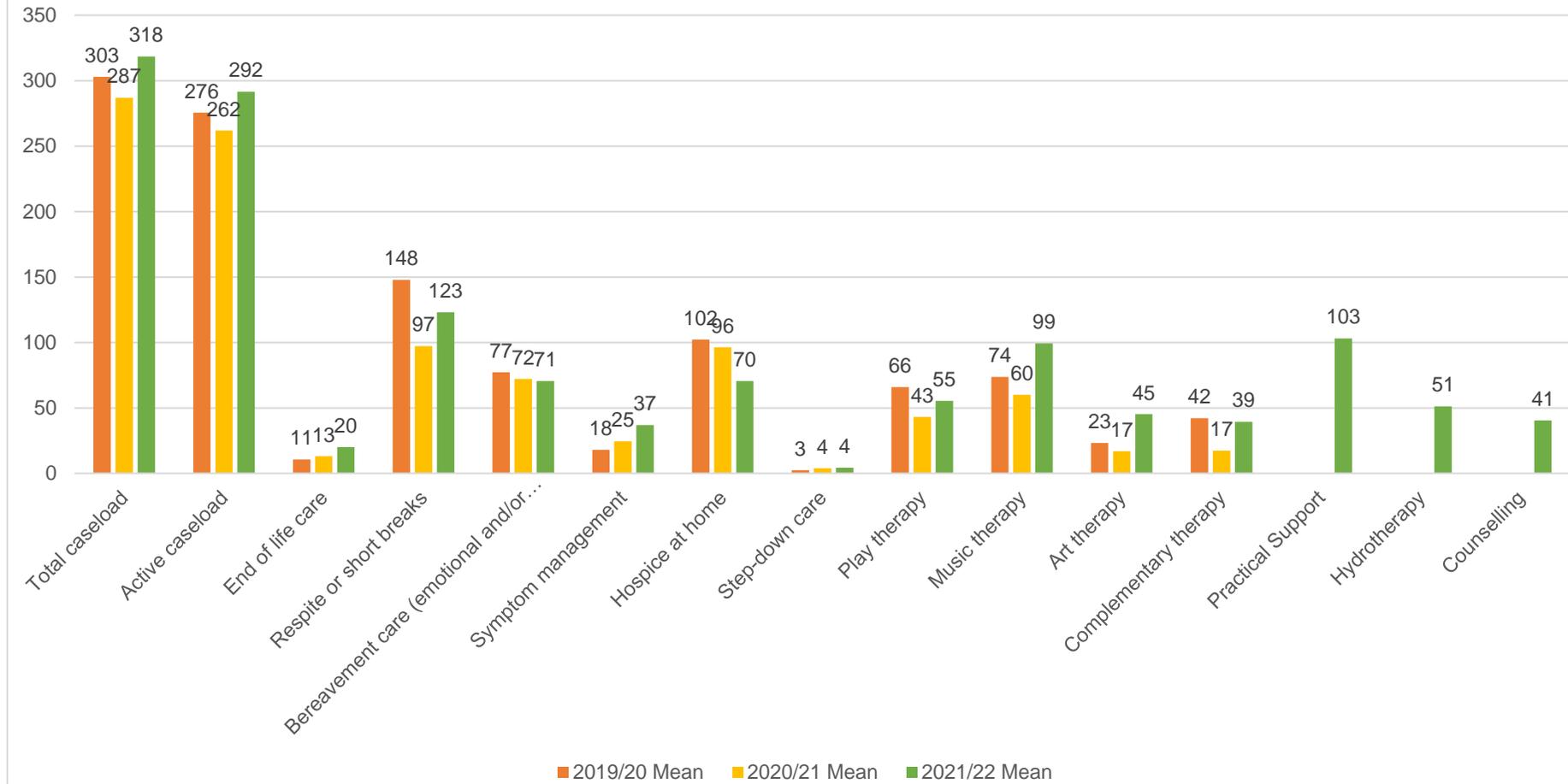
32. Where children's hospice funding has decreased in real terms, nearly a quarter (23%) have tried to mitigate the impact on the services they provide by using funds from their reserves. Nearly one fifth (18%) have cut their services. The same proportion have stopped services, while 18% have also employed fewer care staff. Nearly one in ten (9%) have cut the pay of their care staff.



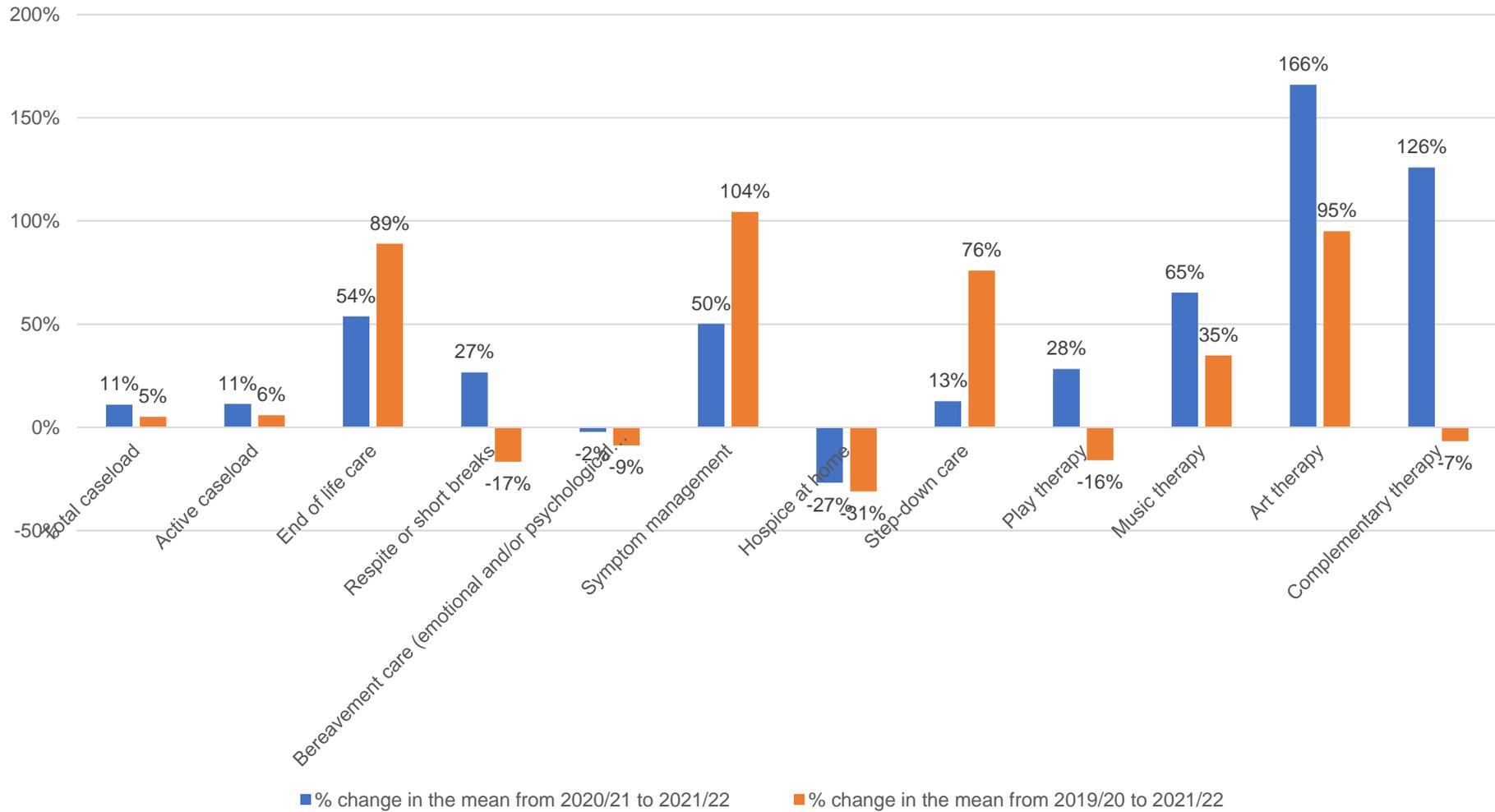
Active caseloads

33. On average, children's hospices' active caseloads have increased by 11% from 262 in 2020/21 to 292 in 2022/23. This is 5% greater on average than the 303 reported in 2019/20.
34. Children's hospices report greater levels of activity across all the types of care and support they provide apart from hospice at home (provided to an average of 70 children per children's hospice, 27% fewer than the 96 reported in 2020/21) and bereavement care and support (provided to an average of 71 children per children's hospice compared to 72 in 2020/21).
35. On average, children's hospices provided end of life care to 54% more children (20 per children's hospice, compared to 13 in 2020/21 and 11 in 2019/20), symptom management care to 50% more children (37 per children's hospice compared to 25 in 2020/21 and 18 in 2019/20) and short breaks for respite to 27% more children (123 per children's hospice compared to 97 in 2020/21). However, some types of activity are still at levels lower than before the pandemic, including short breaks for respite (17% down in 2021/22, compared to the average of 148 children per children's hospice who received them in 2019/20) and hospice at home (31% down in 2021/22, compared to the average of 102 children per children's hospice who received this care in 2019/20).

Mean caseloads 2019/20 and 2021/22



% change in mean caseloads from 2019/20 to 2021/22



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

36. 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:

"We provide support to our local hospitals for discharge from hospital and currently have four children in our hospices who came from hospital as step-down placements. We also support the local authority with those social care emergencies for children with complex needs. As our symptom management services continue to increase we will continue to see a rise in the number of hospital admission avoidance both in the hospice and in the community."

Acorns Children's Hospice

"Our services generally and symptom management and end of life care specifically relieve pressure on the NHS and save NHS considerable costs."

Alexander Devine Children's Cancer Trust

"The hospice enables children to be discharged earlier from hospital, including those waiting for their care packages being set up at home. The hospice can support parents/carers whilst they become familiar with new regimes for their children, and support the child whilst paid carers learn about the child's needs or changes in care requirements. Children requiring safeguarding placements who would otherwise have to be admitted to hospital have been cared for by our organisation, some for over six months. Symptoms have been managed, both at home and in the hospice, avoiding children being admitted to hospital. Our Family Liaison in-reach worker is working in the NICU at the Medway Maritime Hospital, supporting families whilst in hospital and referring them to the hospice for further and on-going support and we are seeking to replicate this in other locations. This has resulted in a 600% increase in referrals from this setting alone, illustrating the unmet need of families not currently accessing hospice services. Similarly, our CNS is supporting the Evelina London Children's Hospital Palliative Care Team (tertiary hospital) to provide care to children in hospital and support care in the community. We have supported local children's community nursing teams to deliver end of life care in the child's own home, providing an improved service for the children and families, enabling discharge from hospital, and providing support for local NHS community teams by pooling the available workforce in an environment of limited Registered Nurses and HCA's with appropriate skills to care for CYP with complex needs. Crisis support has been offered to families, enabling children to be admitted to the hospice to prevent the breakdown of the family unit and/or supporting their on-going ability to care for their child."

Demelza Hospice Care for Children

“We have proved that we support both discharge and avoidance during the last round of emergency funding via the data supplied. NHSE have access to this data. In addition, we are delivering mental health services to bereaved families who don't then use primary care or NHS Mental health services around the management of complex/complicated grief. Parents are supported to return to work and children back to school. Asian families are encouraged to engage with wider health and social care services that may benefit them.”

Forget Me Not Children's Hospice

“Haven House works as an integrated partner in local health and social care systems. We have a jointly funded post with Great Ormond Street Hospital where one of our Hospice at Home nurses works 2 days for GOSH and 2 days for Haven House. This post enables our nurse to identify children who are appropriate to come to the hospice and facilitates the discharge from GOSH. This nurse also speaks to families so they are made aware of the hospice and the services we provide. We also have a neonatal nurse who is the link with Queens Hospital. Again this post facilitates discharge to the hospice and informs families of the hospice and services provided. We provide crisis management for our children. This may be inhouse crisis respite / symptom management or Hospice at Home respite / symptom management. This prevents unplanned admissions, by managing symptoms at home or in the hospice.”

Haven House Children's Hospice

“Care reduces unplanned admissions during episodes of crisis care, and facilitates earlier discharge through step down care. Psycho-social services reduce pressure on both health and social care providers. Additionally, we are working closely with the ICS to develop a children's palliative care strategy that will integrate services provided by both statutory and voluntary sector into a seamless pathway. This will include short breaks, specialised palliative care, EOL care and bereavement support.”

Hope House Children's Hospices

“We prevent family crisis and bed blocking on the children's ward by providing emergency care or supporting the children's community nursing team with end of life care through our hospice at home.”

James Hopkins Trust

“We definitely facilitate early discharges, we provide emergency end of life admissions to the hospice, which in turn prevents that child or young person from going into the hospitals for their end of life. We provide ongoing counselling to the families which enables the families to move on and prevents them from entering the health and social care system themselves.”

Rainbows Hospice for Children and Young People

“Shooting Star Children’s Hospice is an integral part of the wider local and regional health and social care system, working closely with 4 ICS PEOLC All age regional boards to ensure that services for CYP at EOL are co-ordinated and that the needs and requirements of children with palliative care needs and families are highlighted across the health and social care system. Our work with tertiary centres ensures that early discharges are facilitated where possible and the work of our SPACE and Community teams alongside families prevents unplanned admissions to hospital.”

Shooting Star Children's Hospices

“All 65 children and young people on our case load would otherwise access other statutory services.”

St Oswald's Hospice

Policy recommendations

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

- **Protect and extend the NHS England Children's Hospice Grant:** with patchy local NHS funding and the negative experience that some children's hospices have reported in trying to access the NHS Long Term Plan match funding and £25million non-recurring funding in 2019/20, we call on ministers and officials to maintain the Children's Hospice Grant as a ringfenced, centrally distributed funding stream from NHS England. This will make sure that NHS funding meant for children's hospices reaches children's hospices.
- **Hold the new integrated care systems (ICSs) to account:** the Secretary of State for Health and Social Care to use their new powers in the Health and Care Act 2022 to direct NHSE/I 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:** as ICSs operate on a statutory footing from July, integrated care partnerships (ICPs) should take our findings into account as they determine the health and healthcare needs of their population. Integrated care boards (ICBs) should commission children's hospice and palliative care services in a way which meets the NICE standards. NHSE should regularly monitor the extent to which ICPs and ICBs 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.

38. If government, NHSE and ICSs 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. Ministers and officials should act now: seriously ill children do not have time to wait for hospices to receive the reassurances they need on statutory funding.

Children's hospice funding in Scotland

We welcome the progress that planners, funders and providers have made in making sure that children, young people and their families in Scotland can access the palliative care they need, where they need it. This includes the Scottish Government's commitment develop and publish a new national strategy for palliative and end of life care and sustainable funding of at least £7 million per year through Children's Hospices Across Scotland (CHAS).

There are [more than 16,700 babies, children and young people \(aged 0-21\) across Scotland who may die from a life-shortening condition](#). In Scotland there is a single-national provider of children's hospice care, with CHAS working across hospices, hospitals and children's homes. CHAS funds joint specialist teams in all the children's hospitals in Scotland (Aberdeen, Glasgow and Edinburgh).

SCYPPEX developed '[A Framework for the Delivery of Palliative Care for Children and Young People in Scotland](#)'. This was published in November 2012 by the Scottish Government with [CEL 37 \(2012\)](#), a directive to NHS Boards in Scotland.

In 2015, the Scottish Government published a new [Strategic Framework for Action for Palliative and End of Life Care](#). In 2016, Together for Short Lives welcomed the announcement that the Scottish Government committed £30 million funding for CHAS as part of increased investment in children's palliative care for the period 2016-21. The funding has provided approximately half of the agreed running costs of running CHAS.

Despite this progress, challenges remain. In its manifesto document ahead of the 2022 Scottish Parliamentary elections, [CHAS highlighted](#) that not all families in Scotland are equally able to access consistent 24/7 support for end of life care at home, if they choose it. Some NHS boards in Scotland are able to consistently offer this service. In NHS Ayrshire and Arran, the Paediatric Supportive Care Team was put in place specifically to address this issue. The team provides round the clock out of hours medical and nursing support to families in their chosen place of care.

It is not currently possible to train in paediatric palliative medicine Scotland. Those wanting to do so currently have to apply to training programmes in England or Wales. Similarly, it is no longer possible to study for a community children's nursing (CCN) qualification in Scotland. Some nurses are having to piece together modules from other courses, or are receiving local training which does not carry a qualification.

[CHAS also highlighted other challenges facing families in Scotland](#) in:

- accessing social care
- managing the financial impact of caring for a seriously ill child
- accessing toilets that meet their needs
- ensuring smooth transitions between children's and adult services - and access to age and developmentally appropriate care
- access to bereavement support.

Together for Short Lives is pleased that in its programme for 2021/22, the Scottish Government states:

"To provide the very highest standards of care right up to the end of life, we will ensure that everyone who needs it can access seamless, timely and high-quality palliative care. Over the coming year, we will develop and publish a new national strategy for palliative and end of life care that takes a whole system, public health approach. And we 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."

Building on this, we join CHAS in calling on the Scottish Government to:

1. Make sure that the new national plan for palliative care in Scotland addresses the needs of children and young people.
2. Introduce more specialist training for health and social care staff, to meet increasingly complex needs.
3. Provide bespoke support for children living into adulthood.
4. Provide better financial support for struggling families, including after a child dies.

Children's hospice funding in Wales

There are 1,000 children in Wales with life-limiting or life-threatening conditions. Much progress has been made implementing the [Welsh Government's End of Life Care Delivery Plan](#) for children, young people and their families, including the Welsh Government's proposed £888,000 per year increase in funding for Wales' children's hospices, Tŷ Hafan and Tŷ Gobaith. However, the extent to which seriously ill children and young people can choose to receive palliative care at home, including at the end of their lives, depends on where they live. It's vital that the Welsh Government takes action to address these challenges.

[Ahead of the 2021 Senedd elections, we joined Tŷ Hafan and Tŷ Gobaith in calling for a new sustainable 'Lifeline Fund' for children's hospices in Wales and for funding parity with the rest of the UK.](#) Tŷ Hafan and Tŷ Gobaith's proposed to move towards a sustainable model of funding that is more aligned with Children's Hospice charities in other UK nations.

We therefore joined Tŷ Hafan and Tŷ Gobaith in [welcoming the Welsh Government's proposed £888,000 per year increase in funding for Wales' children's hospices](#). This is the first time additional statutory funding has been made available to Wales' two children's hospices since 2007. The children's hospices will receive around 21 per cent of the costs of providing palliative care to children and families in Wales.

The good news was announced by Minister for Health and Social Services, Eluned Morgan MS, during an oral statement in the Senedd on Tuesday 25 January. The hospices have also welcomed the decision to distribute this additional funding via the NHS Collaborative, ensuring that they have discretion over how such additional funding will be spent to benefit of Wales' most vulnerable children and their families whom they support.

This is the first time additional statutory funding has been made available to Wales' 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.

There is, however, 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.

The extent to which seriously ill children and young people can choose to receive palliative care at home, including at the end of their lives, depends in large part on whether they can access community children's nursing 24 hours a day, seven days a week. Community children's nursing can be provided by the NHS, children's hospice at home teams, hospital outreach teams or a combination.

Worryingly, there are too few community children's nurses (CCNs) in Wales with the skills and experience needed to provide palliative care to children and young people. [In 2021 we calculated that the current shortfall in CCNs stands at 240.](#) This means that too many children and families are missing out on the care and support they need, when and where they need it. It also means that too many seriously ill children need unplanned, prolonged

emergency hospital admissions, when their needs could potentially have been met at home. As a result, the NHS is failing to achieve non-cash savings in the resources it spends on these children and their families.

In 2018, [the Cross-Party Group for Hospices and Palliative Care published a report](#) following its inquiry into the inequalities in access to hospice and palliative care in Wales. The report highlighted the shortage of CCNs in Wales and the variation in the number and skills of CCNs across local areas. It recommended that the End of Life Care Implementation Board should develop a robust action plan to address shortages in community nursing for both children and young people, and adults with palliative care need. The report found that children and young people with life-limiting conditions should have the same choices about preferred place of care and/or death as adults at the end of life. For this to happen, the variation in numbers and skills of CCNs would need to be addressed to enable the delivery of end of life care for children in their own homes.

Together for Short Lives estimates that 240 additional community children's nurses (CCNs) are needed to provide a holistic community children's nursing service in Wales. This has been calculated using the current number of CCNs (43) and the number estimated to be needed using recommendations from the Royal College of Nursing. In an area with a child population of 50,000, a minimum of 20 Whole Time Equivalent (WTE) community children's nurses are required to provide a holistic community children's nursing service (283 CCNs needed in total across Wales).

The National Institute for Health and Care Excellence (NICE) has published a clinical guideline ['End of life care for infants, children and young people with life-limiting conditions: planning and management'](#). NICE calculates that if the Welsh Government invested £690,000 in implementing the guidance, non-cash savings worth £1.9million would be released back into the NHS in Wales.

We ask that the Welsh Government:

1. 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.
2. 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.