



# **The deep disparity in NHS funding for children who need hospice care**

A report by Together for Short Lives



## Introduction

In May 2023, Together for Short Lives issued a series of freedom of information (FOI) requests to all NHS integrated care boards (ICBs) in England. We asked ICBs:

1. How much money they had spent on hospice care for children and young people with life-limiting or life-threatening conditions between 6 April 2022 and 5 April 2023. We asked them to provide a total, in addition to a breakdown of funding per children's hospice organisation.
2. How many children and young people with life-limiting or life-threatening conditions who lived in their integrated care board footprint accessed hospice care between 6 April 2022 and 5 April 2023. We asked them to provide a total, in addition to a breakdown of funding per hospice organisation.
3. How many children and young people with life-limiting or life-threatening conditions who lived in their integrated care board footprint could benefit from children's hospice care.

Some ICBs were also able to tell us how much money they planned to spend on hospice care for children and young people with life-limiting or life-threatening conditions between 6 April 2023 and 5 April 2024.

All 42 ICBs responded to our request. [You can access the full responses that they provided us with here](#). We have summarised their responses in [Appendix One](#).

Once we received the responses to the FOIs, we shared them with children's hospices and gave them a right of reply. We have listed the responses that children's hospices gave about each ICB in [Appendix Two](#).

To ensure a consistent approach, we have analysed the FOI responses on the basis of what ICBs have told us. However, as Appendix Two shows, some children's hospices have contested what their ICBs claimed to be funding.

For example, **NHS Hampshire and Isle of Wight ICB** has claimed to be spending £480,872.93 on an unnamed hospice to provide care for children and young people. However, Naomi House & Jacksplace Hospices, which provide children's hospice care in that area, have cast doubt on whether this organisation is indeed a children's hospice. Because the ICB has not named individual hospices in its response, we have included this figure in our analysis, but we advise caution when considering Hampshire and Isle of Wight's figures on this basis.

Where it has been clear from other FOI responses that ICBs have included funding for adult hospices, we have omitted adult hospice funding figures from our analysis.

We have only included spending figures from ICBs that have been able to tell us how much money they have spent on hospice care for children and young people with life-limiting or life-threatening conditions. The majority of organisations that provide hospice care to this population only do so exclusively for children and young people. However, a minority provide hospice care to people of all ages.

**NHS Lincolnshire ICB** has been unable to separate out the funding it provides to St Andrew's Hospice for children and young people's hospice care from the funding it provides to the same organisation for adult hospice care. In 2022/2023, the total value of this block

contract was £56,419. We have decided to omit this figure from our calculations on this basis.

**NHS Kent and Medway** have stated that in 2022/23, Demelza Hospice were paid £67,674 for children and young person services. Ellenor Hospice also received funding from the ICB, but it has been unable to provide the split of funding between children and adult services.

Some ICBs have provided us with responses per 'place', which are smaller geographic areas within ICB areas which often align with a local authority area or patient flows for acute care. **NHS North East and North Cumbria** have been able to tell us that they spent £113,509.70 on children's hospice care in the North Cumbria place. They have also told us that the Northumberland place contracts local hospices with Northumbria Healthcare NHS Foundation Trust and only have an overall indicative block value for all hospices which is not split between adults and children.

Because **NHS North East and North Cumbria ICB** has not been able to provide us with a funding figure for children's hospices in the other places, we have only included the figure for the North Cumbria place in our analysis. ICBs remain formally accountable for any functions and resources they delegate to places, and we feel it is reasonable to expect ICBs to be able to tell us how much they are spending on children's hospice care either directly or through place-based partnerships.

**Staffordshire and Stoke-on-Trent ICB** stated that they were unable to separate grant funding for ages 18-25 for Douglas MacMillan Hospice as their grant of £2,869,955 in 2022/23 covered all ages above 18 years old. We have excluded this figure from our calculation, but have included the match funding of £252,275 they cite in their response. We have assumed that this refers to the children and young people's palliative and end of life care match funding that ICBs have been able to access from NHS England, which is described in the NHS Long Term Plan.

Subsequent to submitting its response to our FOI request, **Lancashire and South Cumbria ICB** has stated that its original submission was incorrect for Brian House Children's Hospice. A revised contribution of £109,000 for 2023/24 has been stated. This includes matched funding from NHS England which is not guaranteed beyond 31 March 2024.

## Terms we use in 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

Local NHS integrated care boards (ICBs) have a legal duty to commission palliative and end of life care for children and young people in England. This report shows, for the first time, the shocking extent to which funding for children's hospices from ICBs varies from area to area. It is nowhere near the level that will sustain the crucial hospice services that seriously ill children and their families need.

Some ICBs do not even know – or would not tell us – how much they are spending on children's hospices.

Children's hospices and palliative care services 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.

The recent ministerial commitment to £25 million NHS funding for children's hospices in 2024/25 is welcome. However, it is only a short-term sticking plaster. There is a £300 million annual funding gap in children's palliative care services.

Access to properly funded hospice and palliative care should not depend on where a child lives, or where they die. We are calling on ministers, officials and the parties that will contest the next UK general election to end the postcode lottery in local NHS funding for children's hospice and palliative care. Children and their families need a fair system to sustain the care and support they will rely on in the next parliament and beyond.

## A postcode lottery of funding

- Our FOI requests found that in 2022/23, on average, ICBs spent £151.03 for every case of a life-limiting or life-threatening condition among children and young people aged 0-24 in their local area.
- However, **the amounts spent by each ICB varied by as much as £483 per child or young person.**
- While Norfolk and Waveney ICB spent the most (an average of £511 per case) in 2022/23, South Yorkshire ICB spent an average of just £28 per case<sup>1</sup>.

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

However, despite these factors, we do not believe that the extent to which funding varies between ICBs can be justified.

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<sup>1</sup> We calculated this by dividing the amount of funding each ICB provided to local children's hospices in 2022/23 by the number of children and young people aged 0-24 with life-limiting conditions that live in each ICB area.

## **Lack of local data**

We were shocked to find that some ICBs were unable to tell us how much they spend on children's hospices – or how many children and young people in their areas access this care and support. This is particularly worrying given that UK Government ministers state that ICBs are responsible for determining the level of NHS funded palliative and end of life care, including hospice care, locally, and for ensuring that the services they commission meet the needs of their local population.

- Six ICBs (14%) that responded to the FOI were unable to tell us how much money they spent on hospice care for children and young people aged 0-25 with life-limiting or life-threatening conditions in 2022/23.
- Only 13 ICBs (31%) were able to tell us how many children and young people with life-limiting or life-threatening conditions who live in the areas they serve accessed hospice care in 2022/23.
- Among those that did, the average number of children and young people accessing a children's hospice was 318 per ICB.

The number of children identified by each ICB varied wildly:

- The ICB with the fewest children and young people accessing hospice care was North Central London (13).
- The ICB that claimed the most children and young people accessing hospice care was Mid and South Essex (1,848).

Noah's Ark Children's Hospice have told us that the 13 children and young people that North Central London ICB claimed to have accessed children's hospice care in 2022/23 is only a fraction of the 229 children and young people in the ICB area that Noah's Ark actually supported during that period. The children's hospice states that this clearly shows the low level of funding the ICB provides relative to the care and support that Noah's Ark delivers.

In contrast, North East London, one of North Central London's neighbouring ICBs, stated that 1,284 children and young people accessed children's hospice care in its local area in 2022/23.

## **Ensuring fair distribution of dedicated funds**

The challenge of patchy funding from local NHS organisations is not new. Even when specific children's palliative care funding has been available for clinical commissioning groups (CCGs, which were abolished in July 2022) and subsequently ICBs from the UK Government and NHSE, such as the NHS Long Term Plan children's palliative care match funding, not all have chosen to access it. The non-recurrent £25 million funding for children's and adult hospices in 2019/20 announced by the Prime Minister in August 2019 is another case in point.

Following a campaign by Together for Short Lives, children's hospices and the public, we welcomed the [commitment to £25 million of NHS funding for children's hospices in 2024/25 announced by Minister of State for Social Care Helen Whately during Children's Hospice Week 2023](#). However, neither the UK Government nor NHS England have yet confirmed how children's hospices will receive this funding.

These FOI responses and data (or lack of) justify concerns by children's hospices in England at the prospect of the £25 million NHS England Children's Hospice Grant being given to ICBs to distribute in future without any safeguards to make sure the money reaches these lifeline services. It is essential that ministers and officials confirm how much of the £25 million each children's hospice will receive in 2024/25 as a matter of urgency – in addition to how and when they will receive it.

### **A sustainable, equitable, long-term plan**

While this funding commitment for 2024/25 is positive, children's palliative care providers across the NHS and voluntary sectors in England do not have the reassurance of a long-term NHS funding plan for children's palliative care. They are trying to manage the impact of the growing cost of recruiting and retaining care staff and the high price of other essential costs such as energy while demand for their services grows. This uncertainty is weakening their ability to invest in the lifeline palliative care and support that children and families rely on.

We therefore call on ministers and officials – and the political parties that will contest the next UK general election – to commit to the following:

1. **Multi-year long term NHS funding for children's palliative care in England** that fills the £300 million gap that we have identified and sustains lifeline services including children's hospices. This should include a commitment to maintaining ringfenced NHS England funding for children's hospices beyond 2024/25 which increases by at least the rate of inflation each year.
2. **A dedicated long-term strategy in the NHS Mandate** that addresses the palliative care needed by children and young people.
3. **Direct NHS England to hold ICBs to greater account** for the way in which they commission children's palliative care.
4. **Direct ICBs to work with neighbouring ICBs** in their region to plan and fund these services.

These commitments would help realise the [joint manifesto for palliative and end of life care](#) developed in partnership with Hospice UK, Marie Curie, the National Bereavement Alliance, Sue Ryder and Together for Short Lives.

They would also help to realise the [Ambitions for Palliative and End of Life Care](#) for children and young people in England.

If the UK Government, NHSE and ICBs fail to take this action, children and families' access to crucial hospice and palliative care services could be put at risk. Even more pressure will be loaded on to already overstretched emergency NHS services.

Time is short for seriously ill children and young people. They do not have time to wait for hospice and palliative care services to receive the sustainable funding they desperately need.

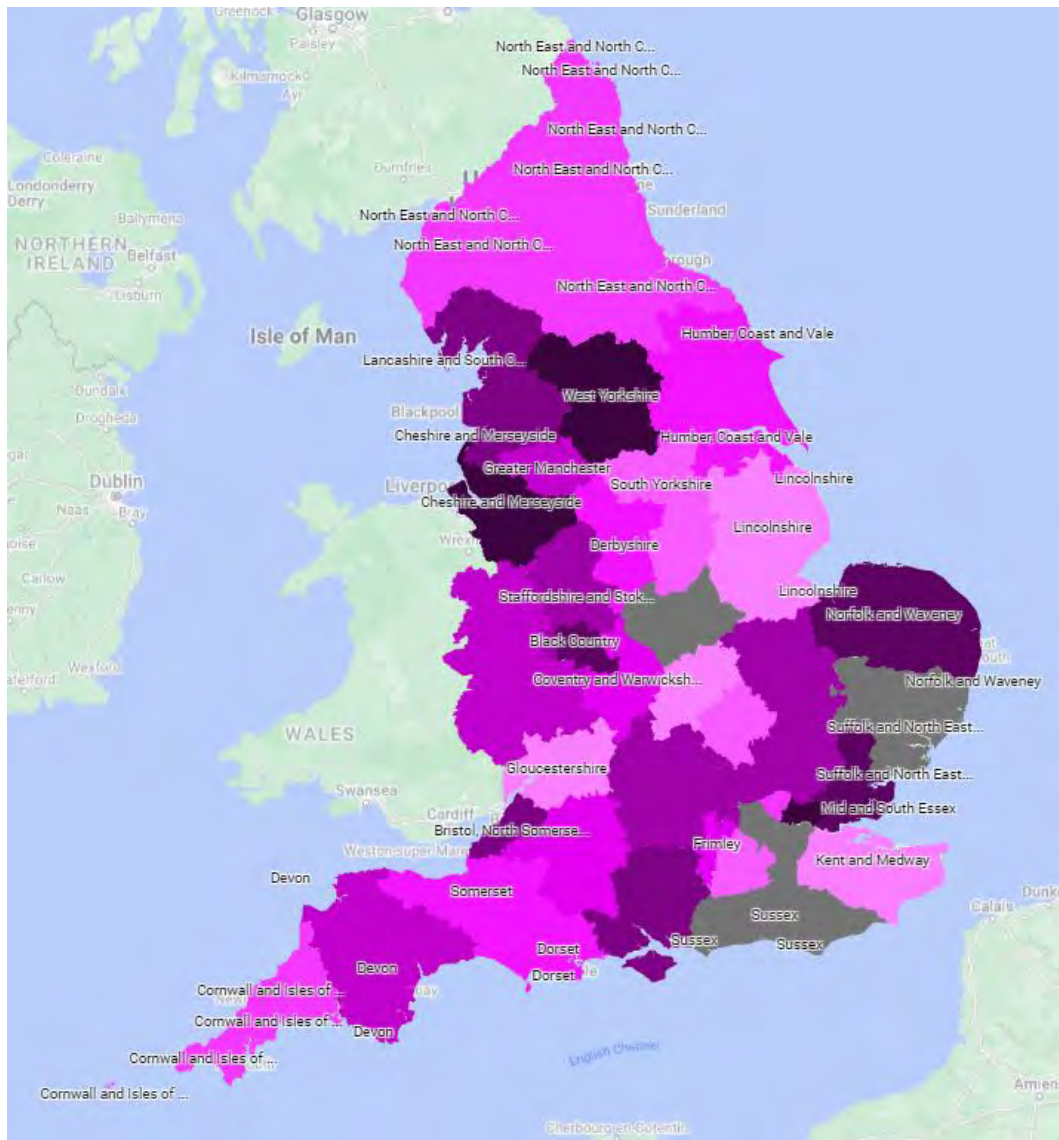
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## ICB funding for children's hospices in 2022/23

1. Of the 42 ICBs who responded to our FOI, 36 ICBs were able to tell us how much they spent on children's hospice care in 2022/23. You can view ICBs' responses in the table in [Appendix One](#).
2. The average spending per ICB was £356,174.
3. However, the amounts spent by each ICB varied wildly:
  - the ICB which spent the least was Northamptonshire (£42,000).
  - the ICB which spent the most was North East London (£1.57 million).
4. Lincolnshire was only able to tell us about the £25,000 it spent in 2022/23 on Rainbows Hospice for Children and Young People. It told us that it also provided a block contract worth £56,419 to St Andrew's Hospice, which provides hospice care to people of all ages.
5. However, because the ICB told us that it was unable to separate out the funding it provides to that organisation for children and young people's hospice care, we have decided to omit this figure from our calculations on this basis.
6. The map overleaf shows how the amounts spent by each ICB vary. The ICBs shaded darker show those areas that are spending greater amounts. The grey areas represent ICBs which could not tell us how much they were spending.
7. [This map is also available to view online here as a Google Map.](#)





This [Google map](#) shows how the total funding provided to children's hospices in England in 2022/23 varied by ICB.

### Key

The numbers below represent funding ranges in £; the term 'no value' means an ICB was unable to tell us how much funding they provided to their children's hospices.

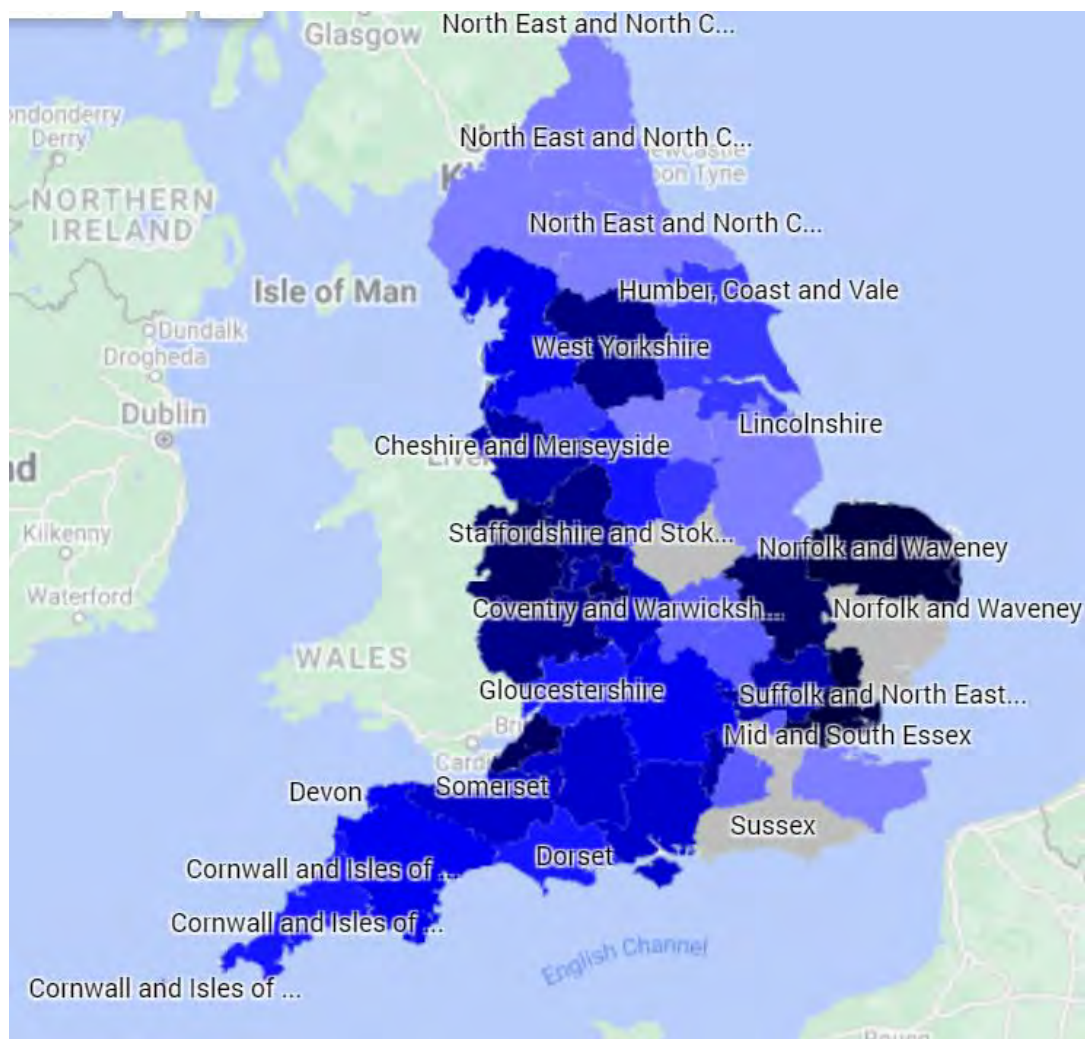
- 25000 - 67674 (4)
- 68320 - 91010 (4)
- 92056.04 - 116888.2 (5)
- 122240 - 169602 (4)
- 210890 - 250000 (3)
- 257675 - 331000 (4)
- 344000 - 450648 (4)
- 483477 - 544472.93 (3)
- 586888 - 755209 (4)
- 912646 - 1567621 (3)
- No value (5)

8. We are not currently able to determine the demand for active hospice care among children and young people. However, we do know how many children and young people aged 0-24 with life-limiting conditions live in each ICB area <sup>2 3</sup>.
9. The table in Appendix One and the charts on pages 12 and 13 show the work we have done to compare each ICBs' funding for children's hospices in 2022/23 with the number of children and young people with life-limiting or life-threatening conditions in each area. From this work, we calculate that, on average, ICBs spent £151.03 per every case of a life-limiting or life-threatening condition among children and young people aged 0-24 in their local area in 2022/23.
10. However, the amounts spent by each ICB varied significantly. While Norfolk and Waveney ICB spent the most (an average of £511.31 per case) in 2022/23, South Yorkshire ICB spent an average of just £27.83 per case.
11. It is important to note that, at any one time, many children and young people with life-limiting or life-threatening conditions are relatively stable and will not need active care and support from a children's hospice.
12. However, it is likely that the number of children and young people in an ICB area who could benefit from active children's hospice care is broadly proportional to this larger number of children and young people with life-limiting or life-threatening conditions. On that basis, it should follow that ICB funding for children's hospices is higher in those areas with higher case numbers.
13. The scatter chart on page 11 shows that this is broadly the case. There are, however, a number of outliers which show that, in too many ICB areas, funding for children's hospices is disproportionate to the number of children who could potentially benefit from the services they provide.
14. The funding that an ICB decides to allocate to a children's hospice will depend on the need for care and support, in addition to how local children's palliative care services are configured across hospital, community and children's hospice settings. Despite these factors, we do not believe that the extent to which funding varies between ICBs can be justified.
15. The map overleaf shows how the amounts spent on children's hospice care by each ICB per child and young person with life-limiting or life-threatening condition in each area vary. The ICBs shaded darker show those areas that are spending greater amounts. The grey areas represent ICBs which could not tell us how much they were spending.
16. [This map is also available to view online here as a Google Map.](#)

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<sup>2</sup> Fraser LK, Gibson-Smith D, Jarvis S, Norman P, Parslow RC. 2020. 'Make Every Child Count: Estimating current and future prevalence of children and young people with life-limiting conditions in the United Kingdom.' Available to download from: <https://www.togetherforshortlives.org.uk/resource/make-every-child-count/>

<sup>3</sup> Fraser LK, Gibson-Smith D, Jarvis S, Norman P. 2021. 'Making Every Young Person Count: Estimating current and future prevalence of young people with life-limiting conditions in England.' Available to download from: <https://www.togetherforshortlives.org.uk/resource/making-every-young-adult-count/>



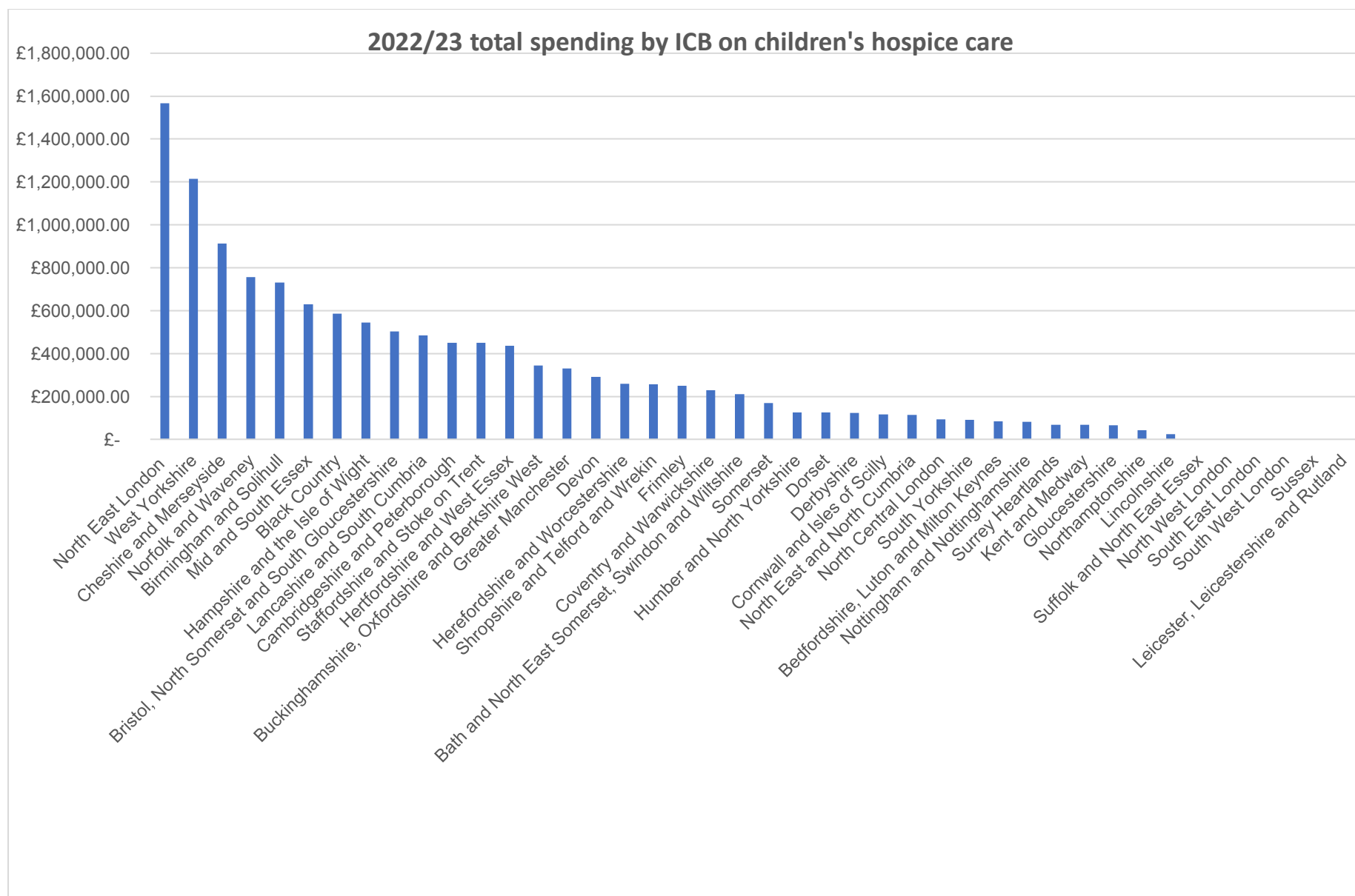
This [Google map](#) shows how the total funding provided to children's hospices in England in 2022/23 per child or young person with a life-limiting or life-threatening condition varied by ICB.

### Key

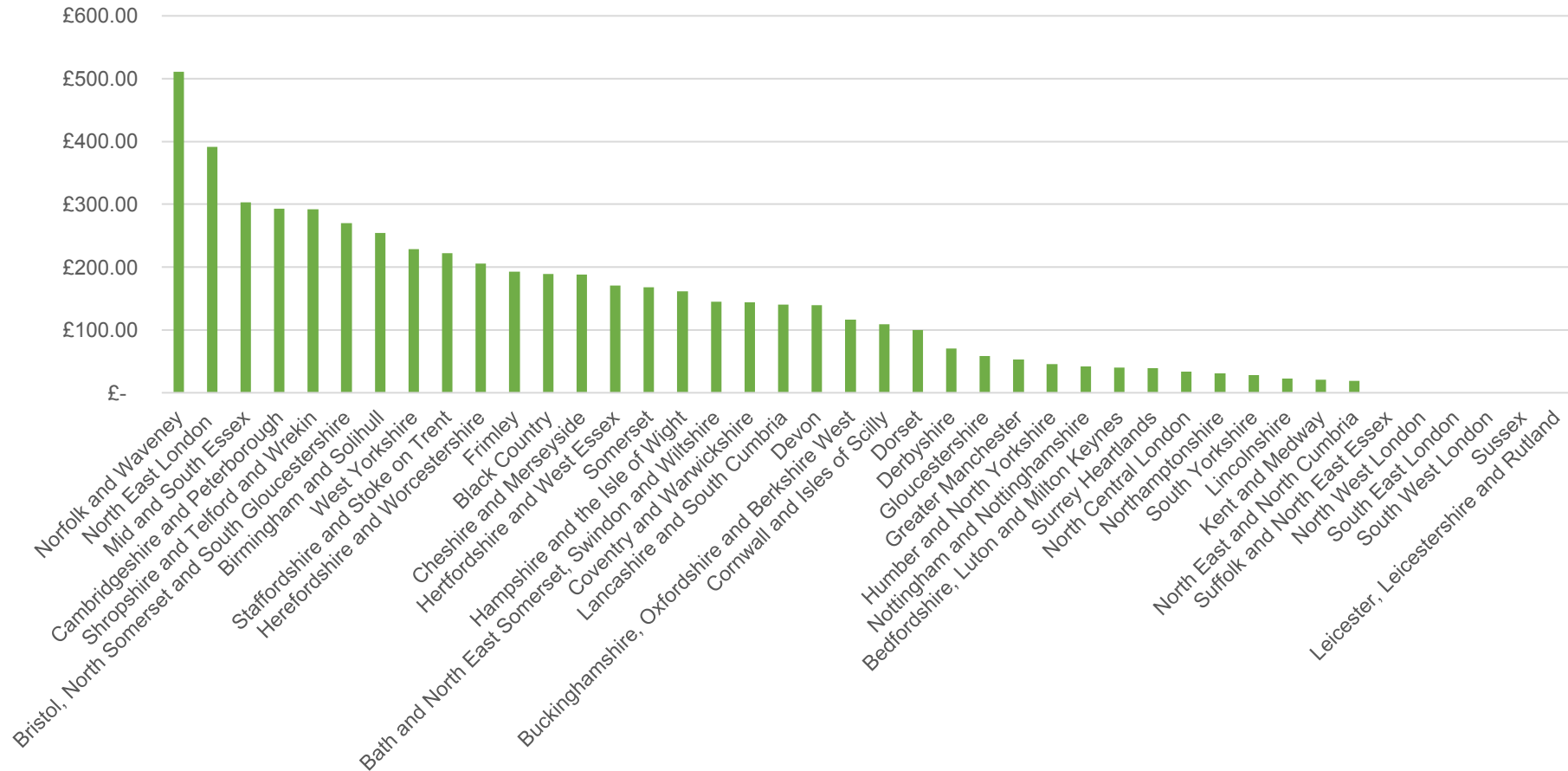
The numbers below represent funding ranges in £ per child or young person with a life-limiting or life-threatening condition; the term 'no value' means an ICB was unable to tell us how much funding they provided to their children's hospices.

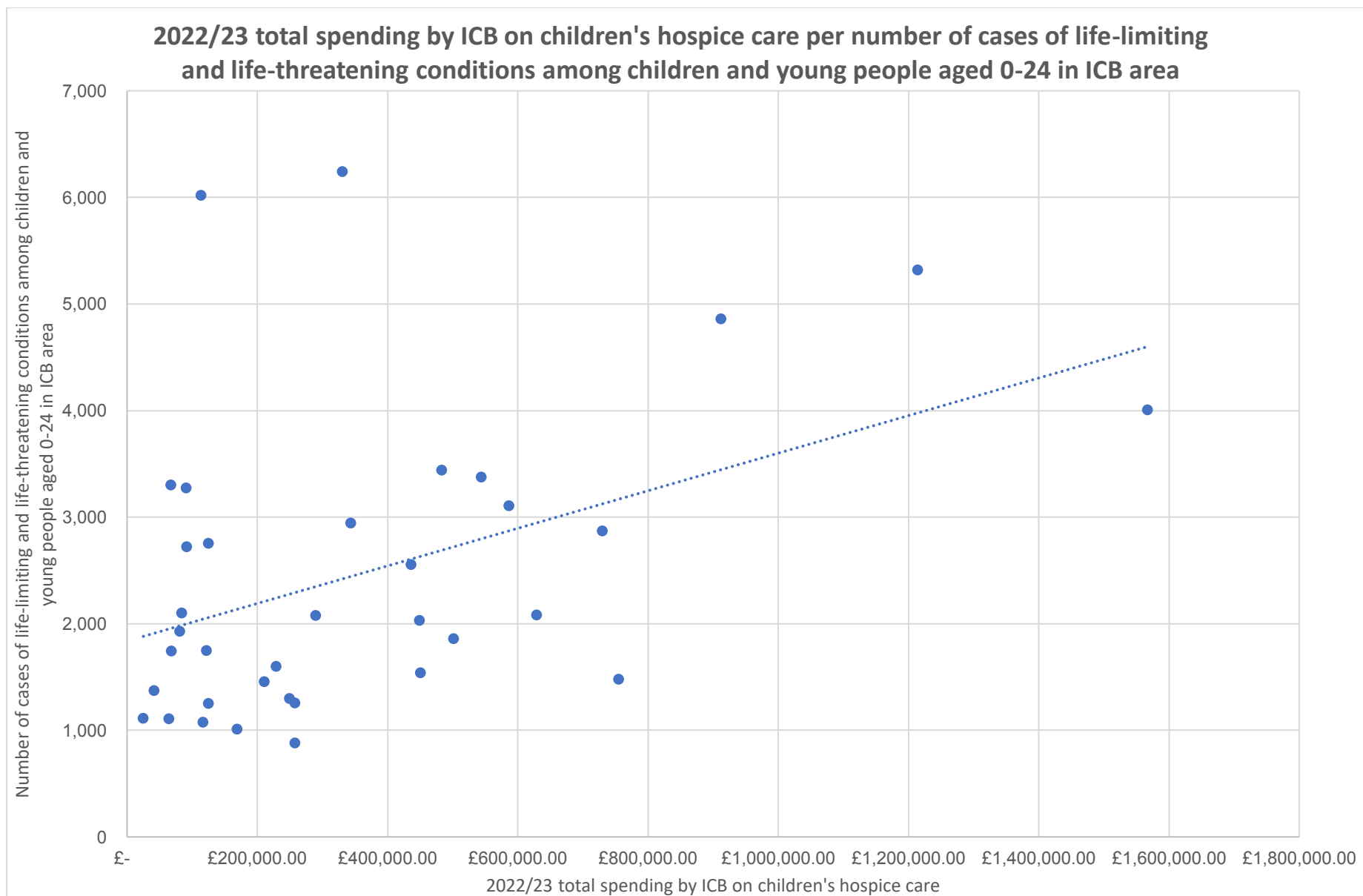
- 18.86 - 27.83 (6)
- 30.59 - 40.22 (4)
- 42.06 - 53.04 (3)
- 58.54 - 108.63 (4)
- 116.81 - 140.66 (3)
- 143.66 - 167.76 (4)
- 170.91 - 192.75 (4)
- 205.22 - 228.39 (3)
- 254.27 - 292.63 (4)
- 302.77 - 511.31 (3)
- No value (6)





**2022/23 total spending by ICB on children's hospice care per number of cases of life-limiting and life-threatening conditions among children and young people aged 0-24 in ICB area (£ per child and young person)**





## Children accessing hospice care in 2022/23

17. Only 13 ICBs were able to tell us how many children and young people with life-limiting or life-threatening conditions who live in the areas they serve accessed hospice care in 2022/23; among those that did, the average number of children and young people accessing a children's hospice was 318 per ICB.
18. However, the number of children identified by each ICB varied significantly:
  - the ICB with the fewest children and young people accessing hospice care was North Central London (13).
  - the ICB that claimed the most children and young people accessing hospice care was Mid and South Essex (1,848).
19. Noah's Ark Children's Hospice have told us that the 13 children and young people that North Central London ICB claim to be accessing children's hospice care is only a fraction of the 229 children and young people in the ICB area that Noah's Ark actually supported in 2022/23. The children's hospice states that this clearly shows the low level of funding the ICB provides compared to the care and support that Noah's Ark offers.
20. In contrast, North East London, one of North Central London's neighbouring ICBs, stated that 1,284 children and young people accessed children's hospice care in its local area in 2022/23.
21. Of the 13 ICBs that were able to tell us both how much they spent and how many children access hospice care:
  - the mean spending per child was £1,286.00.
  - the lowest was in Mid and South Essex (£340.62 per child).
  - the highest was in Cheshire and Merseyside (£18,252 per child).
22. You can view ICBs' responses in the table in [Appendix One](#).



## **ICB funding for children's hospices in 2023/24**

23. Only 20 ICBs were able to tell us what their total spending on children's hospice care would be in 2023/24. Of those that did, each ICB plans to spend an average of £291,398.46 on children's hospices. Again, however, there were a wide range of responses:

- The lowest was South Yorkshire, which plans to spend £64,010.
- The highest was Cheshire and Merseyside, which plans to spend £968,082.

24. Lincolnshire was only able to tell us about the £25,450 it plans to spend in 2022/23 on Rainbows Hospice for Children and Young People. It told us that it also provided a block contract worth £57,435 to St Andrew's Hospice, which provides hospice care to people of all ages.

25. You can view ICBs' responses in the table in [Appendix One](#).

## Policy recommendations

26. Section 21 of the Health and Care Act 2022 states that:

An integrated care board must arrange for the provision of the following to such extent as it considers necessary to meet the reasonable requirements of the people for whom it has responsibility—

(h) such other services or facilities for palliative care as the board considers are appropriate as part of the health service.

27. The duty intends to ensure that the palliative and end of life care needs of people of all ages with progressive illness or those nearing the end of their lives, their carers and those important to them receive the care and support they need to live and die well.

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

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

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

30. Following a campaign by Together for Short Lives, children's hospices and the public, we welcomed the [commitment to £25 million of NHS funding for children's hospices in 2024/25 announced by Minister of State for Social Care Helen Whately during Children's Hospice Week 2023](#). However, we are concerned that neither the UK Government nor NHS England have yet confirmed how children's hospices will receive this funding.

31. We call on ministers and officials to confirm how much of the £25 million each children's hospice will receive in 2024/25 as a matter of urgency – in addition to how and when they will receive it.

32. And while the minister's children's hospice funding commitment for 2024/25 is positive, we remain concerned that children's palliative care providers across the NHS and voluntary sectors in England do not have the reassurance of a long-term NHS funding plan for children's palliative care.
33. The NHS Long Term Plan committed 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 being used to fund children's hospice and palliative care services. The funding amounts during this period have been:
- 2020/21: £2 million
  - 2021/22: £3 million
  - 2022/23: £5 million
  - 2023/24: £7 million
34. Neither the UK Government nor NHSE have committed to maintaining this funding beyond 2023/24. We therefore call on ministers and officials – and the political parties that will contest the next UK general election – to commit to the following:
- **Multi-year long term NHS funding for children's palliative care in England** that fills the £300 million gap that we have identified and sustains lifeline services including children's hospices. This should include a commitment to maintaining ringfenced NHS England funding for children's hospices beyond 2024/25 which increases by at least the rate of inflation each year.
  - **A dedicated long-term strategy in the NHS Mandate** that addresses the palliative care needed by children and young people.
  - **Direct NHS England to hold ICBs to greater account** for the way in which they commission children's palliative care.
  - **Direct ICBs to work with neighbouring ICBs** in their region to plan and fund these services.
35. These commitments would help realise the joint manifesto for palliative and end of life care developed in partnership with Hospice UK, Marie Curie, the National Bereavement Alliance, Sue Ryder and Together for Short Lives. Our five goals are for the next UK Government to:
- Deliver a new funding solution for hospices and palliative and end of life care to end the postcode lottery in access.

- Introduce a national delivery plan for palliative and end of life care in every nation to support delivery of local services.
- Guarantee that palliative and end of life care services meet each individual's needs, including those of people dying at home.
- Act to ensure that nobody dies in poverty and tackle inequalities in palliative and end of life care.
- Improve support for families and carers of people with a terminal illness.

36. If the UK Government, NHSE and ICBs fail to take this action, children and families' access to crucial hospice and palliative care services could be put at risk. Even more pressure will be loaded on to already overstretched emergency NHS services. Seriously ill children do not have time to wait for hospice and palliative care services to receive the sustainable funding they desperately need.



## Appendix one: summary of FOI responses by ICB

Region	Integrated care board	2022/23 total spending by ICB on children's hospice care	Total number of children and young people aged 0-18 accessing hospice care in ICB footprint	Mean spending per child in 2022/23	2023/24 total spending by ICB on children's hospice care	Number of cases of life-limiting and life-threatening conditions (LLCs and LTCs) among children and young people aged 0-24 in ICB area	2022/23 total spending by ICB on children's hospice care per number of cases of life-limiting and life-threatening conditions (LLCs and LTCs) among children and young people aged 0-24 in each ICB area (£ per child and young person)
South West	Bath and North East Somerset, Swindon and Wiltshire	£210,890.00				1,456	£144.84
East of England	Bedfordshire, Luton and Milton Keynes	£84,511.00			£96,385.00	2,101	£40.22
Midlands	Birmingham and Solihull	£730,000.00				2,871	£254.27
Midlands	Black Country	£586,888.00				3,104	£189.07
South West	Bristol, North Somerset and South Gloucestershire	£502,000.00				1,859	£270.04

South East	Buckinghamshire, Oxfordshire and Berkshire West	£344,000.00				2,945	£116.81
East of England	Cambridgeshire and Peterborough	£450,648.00			£474,580.00	1,540	£292.63
North West	Cheshire and Merseyside	£912,646.00	50	£18,252.92	£968,082.00	4,856	£187.94
South West	Cornwall and Isles of Scilly	£116,888.20	121	£966.02	£116,888.20	1,076	£108.63
Midlands	Coventry and Warwickshire	£229,289.00			£233,416.00	1,596	£143.66
Midlands	Derbyshire	£122,240.00	80	£1,528.00	£125,600.00	1,746	£70.01
South West	Devon	£290,000.00			£298,000.00	2,075	£139.76
South West	Dorset	£125,049.00			£184,000.00	1,251	£99.96
South East	Frimley	£250,000.00				1,297	£192.75
South West	Gloucestershire	£64,683.51	73	£886.08	£197,680.00	1,105	£58.54
North West	Greater Manchester	£331,000.00			£454,000.00	6,241	£53.04
South East	Hampshire and the Isle of Wight*	£544,472.93	32	£17,014.78		3,373	£161.42
Midlands	Herefordshire and Worcestershire	£257,967.00			£262,610.00	1,257	£205.22
East of England	Hertfordshire and West Essex	£436,167.00			£556,016.00	2,552	£170.91
North East, Yorkshire	Humber and North Yorkshire	£125,232.00	225	£556.59	£125,232.00	2,755	£45.46

and Humber							
South East	Kent and Medway**	£67,674.00				3,301	£20.50
North West	Lancashire and South Cumbria***	£483,447.00			£560,967.00	3,437	£140.66
Midlands	Leicester, Leicestershire and Rutland					1,739	
Midlands	Lincolnshire****	£25,000.00			£25,450.00	1,113	£22.46
East of England	Mid and South Essex	£629,468.00	1,848	£340.62		2,079	£302.77
East of England	Norfolk and Waveney	£755,209.00	127	£5,946.53		1,477	£511.31
London	North Central London	£92,056.04	13	£7,081.23		2,719	£33.86
North East, Yorkshire and Humber	North East and North Cumbria*****	£113,509.70				6,019	£18.86
London	North East London	£1,567,621.00	1,284	£1,220.89		4,006	£391.32
London	North West London					4,068	
Midlands	Northamptonshire	£42,000.00	48	£875.00		1,373	£30.59
Midlands	Nottingham and Nottinghamshire	£81,000.00	88	£920.45	£81,000.00	1,926	£42.06
Midlands	Shropshire and Telford and Wrekin	£257,675.00	141	£1,827.48	£281,135.00	881	£292.48
South West	Somerset	£169,602.00				1,011	£167.76

London	South East London					3,400	
London	South West London					2,860	
North East, Yorkshire and Humber	South Yorkshire	£91,010.00			£64,010.00	3,270	£27.83
Midlands	Staffordshire and Stoke on Trent*****	£449,515.00				2,027	£221.76
East of England	Suffolk and North East Essex					1,553	
South East	Surrey Heartlands	£68,320.00			£68,320.00	1,744	£39.17
South East	Sussex					2,980	
North East, Yorkshire and Humber	West Yorkshire	£1,214,598.00			£654,598.00	5,318	£228.39

\* **NHS Hampshire and Isle of Wight ICB** have claimed to be spending £480,872.93 on an unnamed hospice to provide care for children and young people. However, Naomi House & Jacksplace Hospices, which provide children's hospice care in that area, have cast doubt on whether this organisation is indeed a children's hospice. Because the ICB has not named individual hospices in its response, we have included this figure in our analysis, but we advise caution when considering Hampshire and Isle of Wight's figures on this basis.

\*\* **NHS Kent and Medway** have stated that in 2022/23, Demelza Hospice were paid £67,674 for children and young person services. Ellenor Hospice also received funding from the ICB, but it has been unable to provide the split of funding between children and adult services.

\*\*\* Subsequent to submitting its response to our FOI request, **Lancashire and South Cumbria ICB** has stated that its original submission was incorrect for Brian House Children's Hospice. A revised contribution of £109,000 for 2023/24 has been stated. This includes matched funding from NHS England which is not guaranteed beyond 31 March 2024.

\*\*\*\* **NHS Lincolnshire ICB** has been unable to separate out the funding it provides to St Andrew's Hospice for children and young people's hospice care from the funding it provides to the same organisation for adult hospice care. In 2022/2023, the total value of this block contract was £56,419. We have decided to omit this figure from our calculations on this basis.

\*\*\*\*\* **NHS North East and North Cumbria** have been able to tell us that they spent £113,509.70 on children's hospice care in the North Cumbria place. They have also told us that the Northumberland place contracts local hospices with Northumbria Healthcare NHS Foundation Trust and only have an overall indicative block value for all hospices which is not split between adults and children.

Because NHS North East and North Cumbria ICB has not been able to provide us with a funding figure for children's hospices in the other places, we have only included the figure for the North Cumbria place in our analysis. ICBs remain formally accountable for any functions and resources they delegate to places, and we feel it is reasonable to expect ICBs to be able to tell us how much they are spending on children's hospice care either directly or through place-based partnerships.

\*\*\*\*\* **Staffordshire and Stoke-on-Trent ICB** stated that they were unable to separate grant funding for ages 18-25 for Douglas MacMillan Hospice as their grant of £2,869,955 in 2022/23 covered all ages above 18 years old. We have excluded this figure from our calculation, but have included the match funding of £252,275 they cite in their response. We have assumed that this refers to the children and young people's palliative and end of life care match funding that ICBs have been able to access from NHS England, which is described in the NHS Long Term Plan.



## Appendix two: feedback from children's hospices

ICB	Children's hospice feedback
<p><b>NHS Bath and North East Somerset, Swindon and Wiltshire ICB</b></p>	<p>Julia's House: When the means of dividing up the NHS England Children's Hospice Grant was changed last year and England's children's hospices were asked to negotiate the split with each other on each geographical patch, from the audited accounts' data shared between the children's hospice providers covering parts of Wiltshire, it was striking that Julia's House was the biggest by some margin - and yet is the only one of the four children's hospices to receive no funding from the BSW ICB.</p> <p>We are helping the ICB to write a strategy for children's palliative care for their area. Relationships are good but progress is frustratingly slow, even though we appreciate that the ICB has to consider all areas of health and social care. There has to date been no real evidence of joined-up planning across Health and Social Care to resolve the social crises facing families with a child with a palliative care need.</p> <p>It is concerning that the ICB does not know how many children and young people have a palliative care need in their area.</p> <p>Naomi House: For Swindon &amp; Wilts the amounts seem about right according to our records</p>

<p><b>NHS Bedfordshire, Luton and Milton Keynes ICB</b></p>	
<p><b>NHS Birmingham and Solihull ICB</b></p>	<p>Acorns: We received £716,784 22/23 which is slightly different to what they have quoted.</p>

<p><b>NHS Black Country ICB</b></p>	<p>Acorns: The funding stated by the ICB tallies with our contract</p>
<p><b>NHS Bristol. North Somerset and South Gloucestershire ICB</b></p>	<p>Jessie May Trust: Correct information - Jessie May received £157,000 in 2023/24 from the BNSSG ICB</p>

<b>NHS Buckinghamshire, Oxfordshire and Berkshire West ICB</b>	<p>Alexander Devine Children's Hospice Service: We receive £79K from BOB. There is no arrangement in place for next year's funding.</p>
<b>NHS Cambridgeshire and Peterborough ICB</b>	

<p><b>NHS Cheshire and Merseyside ICB</b></p>	<p>Claire House Children's Hospice: The financial figures given are not identical to the ones we hold but there are no huge discrepancies. I imagine the small differences will relate to the timing of invoices. With a couple of exceptions, Places were not able to answer the questions regarding number of children and young people who accessed hospice care and number of children and young people who could benefit from hospice care. In a handful of cases, no information was received from Places.</p> <p>However, I do not feel overly disappointed with this response. We have really positive relationships with Place commissioners who have worked collaboratively to commission forward thinking and innovative services from Claire House, including emergency respite care, community based end of life care, and a comprehensive perinatal in-reach programme. All these services have detailed service specs and are covered in a joint contract. In addition, our matched funding programmes were used to test creative solutions to real problems, including a Transition project between pediatric and adult palliative care services.</p>
<p><b>NHS Cornwall and The Isles Of Scilly ICB</b></p>	

<b>NHS Coventry and Warwickshire ICB</b>	<p>Acorns: We received £156,000 for 22/23.</p>
<b>NHS Derby and Derbyshire ICB</b>	<p>Rainbows Hospice: Grant received as per submission. 3 year contract in place. No confirmation of 23-24 inflationary allowance. Estimated £63.360. 80 BCYP from Derbyshire were supported. including 17 new referrals. The grant equates to £792/child. There are 1141 BCYP who could benefit from Rainbows support</p>



<p><b>NHS Devon ICB</b></p>	
<p><b>NHS Dorset ICB</b></p>	<p>Julia's House: We are helping the ICB to write a strategy for children's palliative care for their area. Progress is frustratingly slow, even though we appreciate that the ICB has to consider all areas of health and social care. There has to date been no real evidence of joined-up planning across Health and Social Care to resolve the social crises facing families with a child with a palliative care need.</p> <p>It is concerning that the ICB does not know how many children and young people have a palliative care need in their area.</p> <p>We do not recognize the basis for the rise in projected ICB spend on children's hospice care [for children eligible for Continuing Care] from £125k in 2022/23 to their estimated £184k in the current financial year.</p> <p>Naomi House: Response seems about right according to our records</p>

<b>NHS Frimley ICB</b>	<p>Alexander Devine Children's Hospice Service: There is no arrangement in place past 2024.</p>
<b>NHS Gloucestershire ICB</b>	<p>James Hopkins Trust: we did not receive any funding during this period and this is correctly documented</p> <p>Acorns: The funding stated by the ICB tallies with our contract.</p>

<p><b>NHS Greater Manchester ICB</b></p>	
<p><b>NHS Hampshire and Isle of Wight ICB</b></p>	<p>Naomi House: Really surprised to see that £544,000 on 32 children is being spent although did not specify who with from 3 organisations. We can reconcile £55,550 of £57,660 so makes us Hospice 2 although we are the main provider of CYA Hospice Care in HIOW. £480,000 has been spent with one other Hospice organisation. We did not know the ICB was spending at this level and have asked who the funding is going to.</p>

<b>NHS Herefordshire and Worcestershire ICB</b>	<p>Acorns: The funding stated by the ICB tallies with our contract.</p>
<b>NHS Hertfordshire and West Essex ICB</b>	<p>Haven House Children's Hospice: We agree with the NHS Grant Agreement values shown in the response from NHS Hertfordshire and West Essex ICB. We have also received matched funding from the ICB, which has not been recorded in the response. We believe this may be due to the way in which the question was asked, leading the ICB to believe it was referring to direct grant costs and not all funding. Quarterly reports regarding numbers of children and service usage are submitted to the ICB, therefore accurate numbers of children are held by the hospice.</p>

<p><b>NHS Humber and North Yorkshire ICB</b></p>	
<p><b>NHS Kent and Medway ICB</b></p>	<p>Demelza: 'Make Every Child Count' prevalence data indicates that as at 2017/18 there was 2,741 children who may benefit from input from paediatric palliative care services within the Kent &amp; Medway ICB region. It is anticipated that this number will continue to grow by up to 30% by 2030.</p> <p>The number of children accessing Demelza services for 2022/23 was 381 in the Kent &amp; Medway ICB region. Demelza spent approximately £5m supporting these families and received £69,983 of statutory funding from the ICB. Demelza covers 4 ICB regions and Kent &amp; Medway ICB represents 54% of our total caseload for 2022/23</p> <p>It is important to note that the Children's Hospice Grant is not the only funding that ICB's are required to provide to sustain statutory CYP PEO LC. Approximately 10% of Demelza's overall funding is via the Children's Hospice Grant. This will be a devolved responsibility across the ICB's we work with from 2024. The Children's Hospice Grant essentially enables access to children's palliative and end of life care to those families of children with complex health needs who wish to receive it. At Demelza for 2022/23 there was a gap of 85% between the cost to deliver an adequate level of support to families and the value of the grant received.</p> <p>Demelza is an established organisation that has been providing highly specialist services and support to families within your region for 25 years. We look forward to growing our relationship with Kent &amp; Medway ICB and working</p>

	<p>together to provide an equitable offering to those families across the region who need the highly specialist expertise and support that we offer.</p>
<p><b>NHS Lancashire and South Cumbria ICB</b></p>	



<b>NHS Leicester. Leicestershire and Rutland ICB</b>	<p>Rainbows Hospice: Grant received 2022-23 £68,200- 3.4% uplift for 23-24= £70,519. 197 BCYP from LLR were supported, including 25 new referrals. The grant equates to £357/child. There are 1391 BCYP who could benefit from Rainbows support</p>
<b>NHS Lincolnshire ICB</b>	<p>Rainbows Hospice: Grant received 2022-23 £25,000. 23-24 £25,450= 1.8% uplift. 34 BCYP from Lincoln were supported, including 5 new referrals. The grant equates to £748/child. There are 939 BCYP who could benefit from Rainbows support</p>

<p><b>NHS Mid and South Essex ICB</b></p>	
<p><b>NHS Norfolk and Waveney ICB</b></p>	

<b>NHS North Central London ICB</b>	<p>Noah's Ark Children's Hospice: The ICB have only funded 13 children through planned respite and end of life care (Question 2) which is different from the number who accessed hospice care. This clearly shows the low level of funding the ICB provides to us vs the activity. We supported 229 children in the NCL catchment area in the reporting period. The neighbouring ICB in NE London funded over £1.5m (to two children's hospices) and our ICB funded us £85k. To be so geographically close to an ICB who funds to such a significant amount demonstrates the inequality. We have been told by the ICB that there have been cuts and there will be a reduction in planned respite numbers. The ICB are not able to forecast future activity which is not helpful for us in our financial planning. There is national data (Lorna Fraser) that is being updated this year and demonstrates future need.</p>
<b>NHS North East and North Cumbria ICB</b>	

<b>NHS North East London ICB</b>	<p>Haven House Children's Hospice: We agree with the funding response from NHS North East London ICB, referring to our NHS Standard Contract. We have also received matched funding from the ICB, which has not been recorded in the response. We believe this may be due to the way in which the question was asked, leading the ICB to believe it was referring to direct contract costs and not all funding.</p> <p>Quarterly reports regarding numbers of children and service usage are submitted to the ICB, therefore accurate numbers of children are held by the hospice. 247 children in this ICB footprint with life limiting or life threatening conditions were open to hospice care in 2022/23.</p>
<b>NHS North West London ICB</b>	

<b>NHS Northamptonshire ICB</b>	<p>Rainbows Hospice: Grant received 2022-23 £21,000. 23-24 £21,945=4% uplift. 37 BCYP from Northamptonshire were supported, including 4 new referrals. The grant equates to £593/child There are 1194 BCYP who could benefit from Rainbows support</p>
<b>NHS Nottingham and Nottinghamshire ICB</b>	<p>Rainbows Hospice: Grant received 2022-23 £68,200. 23-24 £68,200- no uplift . 125 BCYP from Nottinghamshire were supported, including 29 new referrals. The grant equates to £545/child There are 1690 BCYP who could benefit from Rainbows support</p>

<p><b>NHS Shropshire. Telford and Wrekin ICB</b></p>	
<p><b>NHS Somerset ICB</b></p>	



<p><b>NHS South East London ICB</b></p>	<p>Demelza: 'Make Every Child Count' prevalence data indicates that as at 2017/18 there was 2.899 children who may benefit from input from paediatric palliative care services within the South East London ICB region. It is anticipated that this number will continue to grow by up to 30% by 2030.</p> <p>The number of children accessing Demelza services for 2022/23 was 216 in the South East London ICB region. Demelza spent approximately £2.9m supporting these families and received £229,300 of statutory funding from the ICB. Demelza covers 4 ICB regions and South East London ICB represents 31% of our total caseload for 2022/23</p> <p>It is important to note that the Children's Hospice Grant is not the only funding that ICB's are required to provide to sustain statutory CYP PEO LC. Approximately 10% of Demelza's overall funding is via the Children's Hospice Grant. This will be a devolved responsibility across the ICB's we work with from 2024. The Children's Hospice Grant essentially enables access to children's palliative and end of life care to those families of children with complex health needs who wish to receive it. At Demelza for 2022/23 there was a gap of 85% between the cost to deliver an adequate level of support to families and the value of the grant received.</p> <p>Demelza is an established organisation that has been providing highly specialist services and support to families within your region for 25 years. We look forward to growing our relationship with South East London ICB and working together to provide an equitable offering to those families across the region who need the highly specialist expertise and support that we offer.</p>
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<p><b>NHS South West London ICB</b></p>	<p>Demelza: 'Make Every Child Count' prevalence data indicates that as at 2017/18 there was 735 children who may benefit from input from paediatric palliative care services within the South West London ICB region. It is anticipated that this number will continue to grow by up to 30% by 2030.</p> <p>The number of children accessing Demelza services for 2022/23 was 20 in the South West London ICB region. Demelza spent approximately £270,000 supporting these families and received no statutory funding. Demelza covers 4 ICB regions and South West London ICB represents 3% of our total caseload for 2022/23.</p> <p>It is important to note that the Children's Hospice Grant is not the only funding that ICB's are required to provide to sustain statutory CYP PEO LC. Approximately 10% of Demelza's overall funding is via the Children's Hospice Grant. This will be a devolved responsibility across the ICB's we work with from 2024. The Children's Hospice Grant essentially enables access to children's palliative and end of life care to those families of children with complex health needs who wish to receive it. At Demelza for 2022/23 there was a gap of 85% between the cost to deliver an adequate level of support to families and the value of the grant received.</p> <p>Demelza is an established organisation that has been providing highly specialist services and support to families within your region for 25 years. We look forward to growing our relationship with South West London ICB and working together to provide an equitable offering to those families across the region who need the highly specialist expertise and support that we offer.</p>
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<b>NHS South Yorkshire ICB</b>	
<b>NHS Staffordshire and Stoke-on- Trent ICB</b>	<p>Acorns: The funding stated by the ICB tallies with our contract.</p>

<p><b>NHS Suffolk and North East Essex ICB</b></p>	
<p><b>NHS Surrey Heartlands ICB</b></p>	

<p><b>NHS Sussex ICB</b></p>	<p>St Barnabas Hospices (Sussex) Ltd: Whilst the funding from ICB is currently not forthcoming we are working closely with the ICB to improve CYPEOLPC and the CEO has visited our hospice and engaged in discussions.</p> <p>Demelza: 'Make Every Child Count' prevalence data indicates that as at 2017/18 there was 1.852 children who may benefit from input from paediatric palliative care services within the Sussex ICB region. It is anticipated that this number will continue to grow by up to 30% by 2030.</p> <p>The number of children accessing Demelza services for 2022/23 was 78 in the Sussex ICB region. Demelza spent approximately £1m supporting these families and received £199.785 of statutory funding. Demelza covers 4 ICB regions and Sussex ICB represents 11% of our total caseload for 2022/23</p> <p>It is important to note that The Children's Hospice Grant is not the only funding that ICB's are required to provide to sustain statutory CYP PEOLC. Approximately 10% of Demelza's overall funding is via the Children's Hospice Grant. This will be a devolved responsibility across the ICB's we work with from 2024. The Children's Hospice Grant essentially enables access to children's palliative and end of life care to those families of children with complex health needs who wish to receive it. At Demelza for 2022/23 there was a gap of 85% between the cost to deliver an adequate level of support to families and the value of the grant received.</p> <p>Demelza is an established organisation that has been providing highly specialist services and support to families within your region for 25 years. We look forward to growing our relationship with Sussex ICB and working together to provide an equitable offering to those families across the region who need the highly specialist expertise and support that we offer.</p>
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<b>NHS West Yorkshire ICB</b>	
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## Addendum

Since publishing, Hampshire and Isle of Wight have provided updated figures to this FOI request.

Under the new response, when asked how much the ICB spent on hospice care for children and young people between 6 April 2022 and 5 April 2023, a figure of £57,035 split between Shooting Star (£16,535) and Naomi House (£40,500) has been provided. The ICB has also identified a figure of £9,000 that was provided to Jacksplace for 5 individuals aged between 18-25 years of age.

By combining these figures, a total spend of £66,035 can be calculated. This is significantly less than the figure of £544,472.93 previously reported and works out to an average spend of £19.57 per child or young person with a life-limiting or life-threatening condition in the ICB area.

Not only does this make Hampshire and Isle of Wight the lowest spending ICB in England, but it also increases the extent to which local NHS spending on children's hospice care varies.

Previously, we reported the amounts spent by each ICB to vary by as much as £483 per child or young person. Using the new figures provided by Hampshire and Isle of Wight ICB, the amounts spent by each ICB can now be seen to vary by as much as £491.43.

The updated FOI response from Hampshire and Isle of Wight ICB can be found [here](#).