

Commissioning and statutory funding arrangements for hospices in England

Survey results 2015



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Introduction

Charitable hospices care for around 360,000 people each year. They provide 26 million hours of care – 90% of which is provided through day care and at home services.¹

Hospices are quite unique among providers of health and social care – contributing as they do so significantly not only to the provision but also to the funding of palliative and end of life care. Together, hospices around the UK spend over £900 million per year in the UK to provide care to those who need it.²

Most (but not all) hospices in England receive a proportion of their overall funding from statutory sources including clinical commissioning groups (CCGs), local authorities and NHS England. Over the past three years we have found this statutory funding coming under increasing pressure and in some instances beginning to impact on services to people, their carers and communities.

We already know that not everyone who would benefit from palliative care receives it – with an estimate that each year over 90,000 people have a need for palliative care support that goes unmet.³ Demand for this care will continue to rise with expectations that this rise will be steep. In England alone the number of people dying each year⁴ is expected to increase by over 4,000 a year between 2021 and 2025 and by over 8,000 a year between 2031 and 2035.⁵

Demand is increasing for children's hospice care too. Specifically, it is estimated that more than 40,000 children (0–19 years) were living with a life-limiting or life-threatening condition in England in 2009/10 – compared to 30,000 in 2000/01. The highest rate of increase during this period was among those aged 16–19 years, who now account for 4,000, or one in ten, of 0–19-year-olds who need palliative care.⁶ This is due to increasing life expectancy

and improving quality of life resulting from advances in treatment and support. Children's hospices are also experiencing an increase in demand for palliative care for very young babies.

More sustainable funding for care and stronger partnership working would enable hospices to continue to develop their role in helping to respond to this growth in demand.

Funding arrangements for hospices are also becoming more variable: some hospices benefit from positive relationships with statutory funders, while others see ongoing funding freezes or cuts.

The coalition government's commitment in 2010 to introduce a new funding system for hospice and palliative care has not yet been realised.⁷ This is causing ongoing uncertainty for hospices across England.

Since 2013 Hospice UK has carried out an annual survey of local hospices to understand their experiences of the commissioning and statutory funding environment. Together for Short Lives has undertaken a similar survey of children's hospices since 2008. This year Hospice UK and Together for Short Lives have worked together to undertake a joint survey.

Where we use the term 'hospice' in this report, we refer to organisations which run one or more hospice care service.

Executive summary

1. Funding for hospices is fragile: More than two thirds of hospices have had their statutory funding frozen or cut by NHS commissioners for 2014/15:

- Nearly a fifth of hospices surveyed (17%) – both children’s and adult hospices – had their funding reduced.
- Funding has remained static for more than half of hospices surveyed (52%); for many hospices this comes after several years of freezes or cuts in statutory funding.

2. Funding is unfair:

- More than eight in ten hospices surveyed (85%) do not think their hospice is being funded fairly and sustainably by the NHS.
- CCGs contribute on average just 10% to the cost of the care that children’s hospices provide – compared to an average of around 30% for adult hospices.
- CCG funding for adult hospices varies widely; across England, CCGs make contributions to hospice care costs which range from less than 1% to more than 50%.
- Over a third of total CCG funding for children’s hospices in England supports just two children’s hospices; one children’s hospice receives nothing at all from their CCGs.
- Almost all children’s hospices did not think that funding from their local CCG(s) in 2014/15 was at a level whereby they would not need their NHS England children’s hospice grant.
- In spite of providing a range of social care services, less than a quarter (23%) of hospices surveyed reported receiving funding from local authorities to fund this care.

3. Funding is unsustainable:

- Almost three-quarters (74%) of hospices in England surveyed expect their funding to be either cut or frozen again during this financial year (2015/16). With 59% expecting a funding freeze and 15% anticipating a cut in funding.
- Some hospices have warned they are likely to have to review the services they offer and may not be able to continue to provide the same level of care in the near future.
- Services that have been identified by some hospices as being at risk from inadequate levels of NHS funding include community nursing specialist teams and hospice at home care.
- Some hospices are subsidising shortfalls in statutory funding through their reserves, freezing staff recruitment or putting service development on hold as demand for hospice care increases and statutory funding fails to keep pace with the cost of providing care.

4. Commissioning and contracting is too complex:

- On average, every hospice in England has to work with four different local CCG commissioners. Children’s hospices have to work with an average of seven different local CCG commissioners each.
- To secure funding from CCGs – and manage the various different commissioning and contracting agreements that this requires – hospices are having to commit resources which are disproportionate to the limited funding contributions they are receiving in return.

Executive summary continued

5. Hospices should be regarded as integral to local palliative care provision – yet only in some local areas are they seen as key partners:

- Almost a third of hospices surveyed (29%) reported an increase in funding from NHS commissioners last year. And some hospices report very close joint working with the NHS and other local partners in developing and delivering integrated care pathways. Nevertheless, only 37% of hospices surveyed are currently involved with their local health and wellbeing boards – and under half (49%) have any relationship with local authority commissioners in their areas.

Background

Between April and May 2015, Hospice UK and Together for Short Lives jointly undertook a survey among charitable hospices in England, to gather a picture of their experiences of statutory funding and commissioning. Our survey included both adult and children's hospices in England, and achieved a response rate of 67% (117 out of 175 English hospices). Among the 33 organisations which provide hospice care to children and young people, 26 responded to our survey (79%).

This is the eighth successive year which Together for Short Lives – and formerly Children's Hospices UK – has conducted such an analysis to build up a comprehensive picture of children's hospice funding and the relationships services have with local commissioners. This is the third successive year which Hospice UK has undertaken such a survey. This is the first year that we have surveyed children's and adult hospices together.

This summary report identifies key findings based on the quantitative feedback from the survey results, and includes examples from qualitative feedback. We also recommend a series of actions for government, NHS England, CCGs and local authorities. These would lead to fairer and more sustainable funding – and hospice care for both children and adults which is commissioned more effectively.

Recommendations

Although there are many different views on how local hospices should be funded by the NHS and local authorities, it is widely accepted that the current system, which is characterised by inconsistency and variation, needs to be reformed.

In 2011, the findings and recommendations of a government-commissioned Independent Palliative Care Funding Review⁸ were published. It recommended that a per-patient funding tariff for palliative care should be developed to provide more sustainable and transparent funding. Work has progressed and in 2015 a non-mandatory palliative care currency was published for further testing. However, as further work to develop a new funding system continues, hospices and other providers of palliative and end of life care face ongoing inconsistency and variation in funding. The lack of a clear direction continues to cause concern.

The government has not yet responded to the recommendations made by the independent review. Since the review was published, tariff funding systems that are linked to activity have come under scrutiny with the NHS appearing to favour funding systems that are more closely linked to quality and outcomes, and that operate at a population level. Unless decisions are made about how the state contributes to the cost of palliative care in England, it will be very difficult for any new system to bring about fairer and more sustainable funding for hospices.

We believe that a range of organisations must take specific actions to bring about fair and sustainable statutory funding for hospices in England. These include the government, NHS England, local commissioners and local health and wellbeing boards. Hospice UK and Together for Short Lives make the following recommendations:

For government

- To provide clarity and certainty to both commissioners and providers, Hospice UK and Together for Short Lives call on ministers to formally respond to the Palliative Care Funding Review's recommendations as soon as possible.
- To respond to the recommendations by the Health Select Committee (following its inquiry into end of life care) that the government should:
 - » (with NHS England) set out how universal, seven day access to specialist palliative care can become available to all patients
 - » provide for universal access to bereavement services in its funding plans for palliative care
 - » provide for free and fast social care at the end of life
 - » ensure that future funding proposals fully recognise the importance of the voluntary sector – and specifically set out how it intends to ensure sustainable, long term funding for the hospice sector.
- To set out how the state should contribute to the cost of short breaks for children and young people with life-limiting conditions.
- To take an overview of separate funding streams for hospices and set out how funding from NHS England, CCGs and local authorities should work together currently to fund the care they provide.⁹
- To provide guidance and allocate funding to make sure that any elements of hospice and palliative care that may fall outside of the scope of a new funding system are funded by CCGs and local authorities.

For NHS England

- To maintain the children's hospice grant until the new funding system is capable of funding children's hospice and palliative care fairly and sustainably.
- To ensure that commissioning practices reflect a proportionate approach to commissioning, contracting and monitoring arrangements. Guidance to commissioners and their support teams should be strengthened to give them confidence in using appropriate funding arrangements. For example recognising that the NHS Standard Contract is not always an appropriate tool for arrangements with hospices and other voluntary sector providers. Building on previous guidance and tailored arrangements around the NHS Standard Contract and model grant agreements.

For local commissioners

- To explicitly set out how they commission hospice and palliative care services across their locality, including trends in funding. For children and young people, CCGs and local authorities should use the commissioning guidance developed by Together for Short Lives^{10,11}
- To seek to engage with partner organisations, including other health and social care commissioners to collaborate (for example through lead commissioner arrangements), to help improve efficiency and better support strategic planning of hospice and palliative care services.
- To use contracting arrangements with hospices which are proportionate to the contribution they are making towards hospice care costs; consistent with NHS England guidance¹², this should include grant agreements.

For local health and wellbeing boards

- To include people who need hospice and palliative care in local joint strategic needs assessments (JSNAs). For children and young people both the special educational needs and disability (SEND) code of practice¹³ and guidance from the Department for Health¹⁴ currently state that children who need palliative care should be included in JSNAs.

Our findings

Statutory funding and commissioning is fragile, unfair and unsustainable

Funding reductions

Concern over statutory funding levels is increasing within the hospice sector. And variation in funding remains an issue as the sector awaits progress on the development of a new funding system for hospice and palliative care.

85% of hospices surveyed do not think that their hospice is being funded fairly and sustainably. This is particularly strongly felt among children's hospices – with no children's hospice reporting that it feels that it is being funded fairly and sustainably from statutory sources.

More than two-thirds of all hospices surveyed had their statutory funding from NHS commissioners frozen (52%) or cut (17%) between 2013/14 and 2014/15. Looking forward, the expectation is that this position will get worse – with almost three-quarters of hospices surveyed expecting a funding freeze (59%) or cut (15%) for 2015/16.

The situation within the children's sector differs slightly: 35% of children's hospices had their funding frozen between 2013/14 and 2014/15 by NHS commissioners, with 23% having their funding cut. This means that over half (58%) of children's hospices either had their funding frozen or cut between 2013/14 and 2014/15.

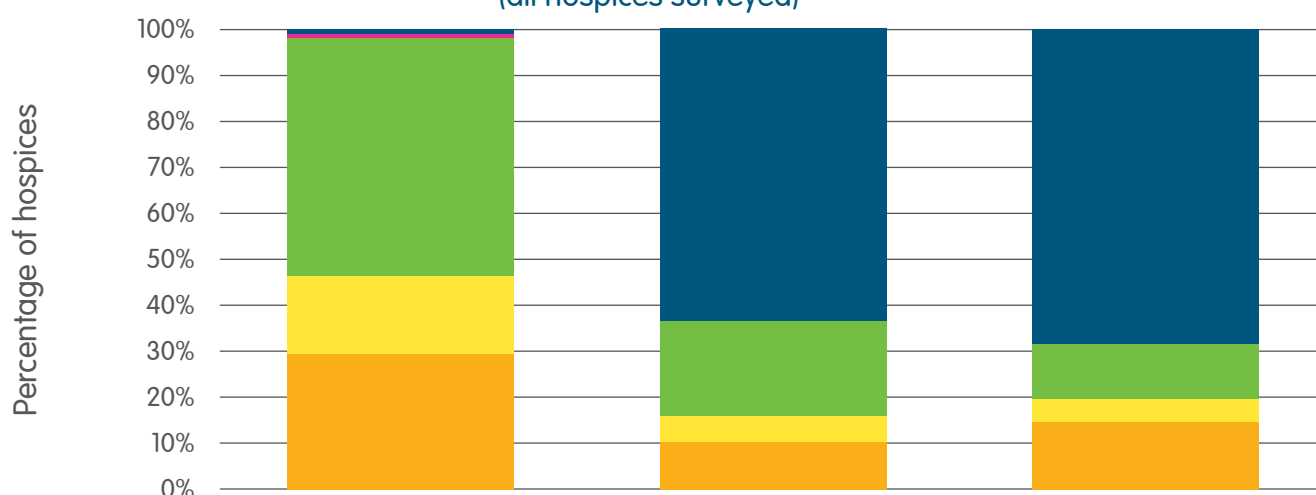
At the extreme one hospice reported a cut of 41% of their statutory funding between 2013/14 and 2014/15. Where hospices reported a decrease in NHS funding the mean level of decrease was 8%; for children's hospices where they experienced a decrease the mean decrease was 29%. For many other hospices statutory funding has not increased for several years, cumulatively producing significant real terms cuts.

"We have received the same level of NHS funding for the past 7-8 years."

"NHS commissioners have applied an annual deflator to our funding year on year for the past four years."

Change in funding (2013/14 to 2014/15)

(all hospices surveyed)



	NHS commissioners	Local authority commissioners	Other commissioners
Not applicable	1%	49%	53%
Don't know	1%	0%	0%
No change	52%	16%	9%
Decreased	17%	5%	4%
Increased	29%	8%	11%

Hospices acknowledge that in many instances financial constraints within the NHS underlie the funding cuts or freezes. With almost half of hospices surveyed (44%) identifying financial restrictions on NHS commissioners and over a quarter (28%) citing standstill budgets as the reasons for the decrease or standstill in their funding.

Where funding to children's hospices was being cut, 27% reported that this was because of commissioners' financial restrictions; 19% reported that it was due to commissioners' having a standstill budget.

As far as possible, hospices are currently absorbing the impact of statutory funding restrictions to protect services to patients, by increasing their fundraising activities or drawing on reserves. However the cumulative impact of frozen or reduced funding is making this position increasingly difficult to sustain for some hospices as charitable resources are stretched to their limit.

Twenty-one per cent of respondents that are providing an inpatient service reported at least some negative impact of the changes in statutory funding levels on the service. Eighteen per cent of respondents providing a hospice at home service reported at least some negative impact of the changes in funding levels on the service. With 26% of respondents reporting at least some negative impact on end of life care services.

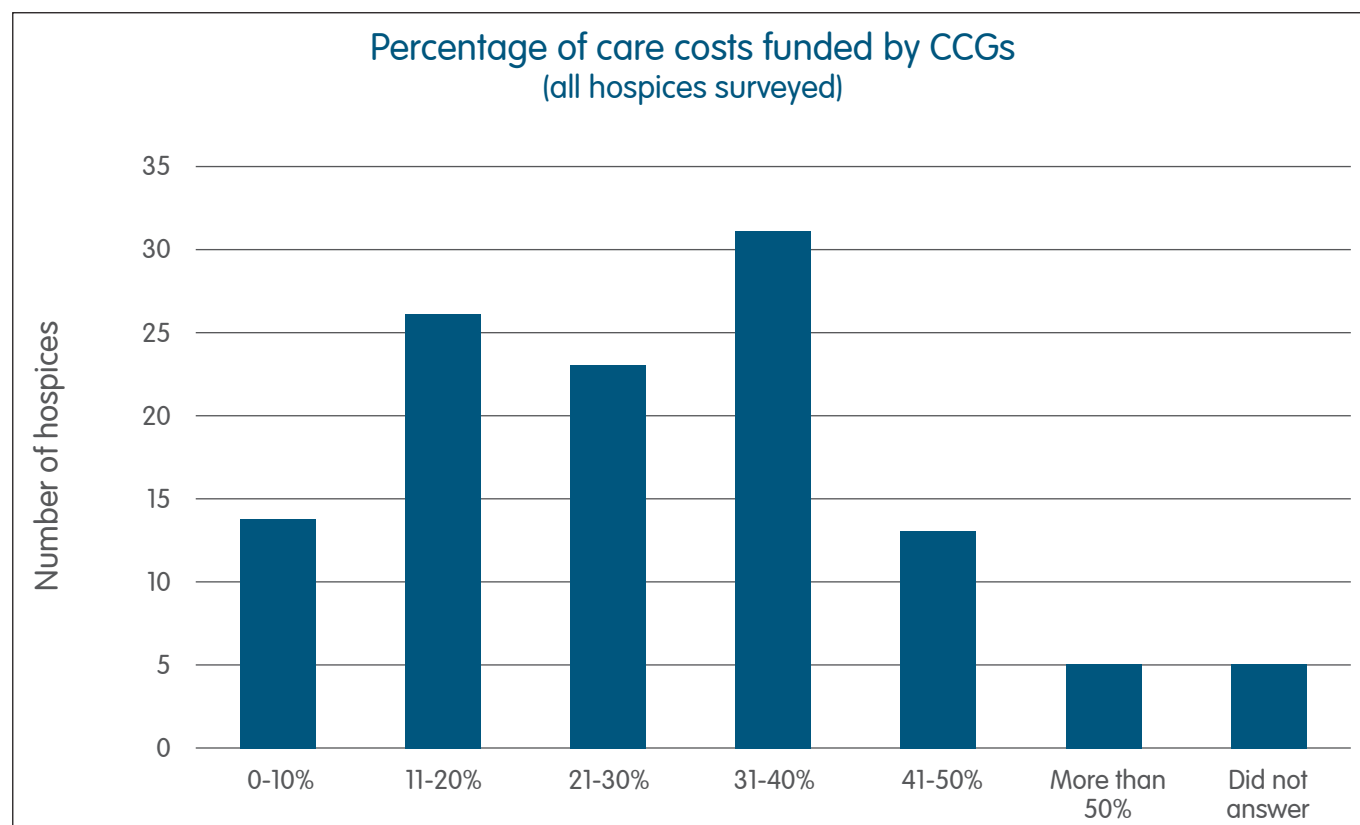
"Our Community Clinical Nurse Specialist Service is at risk through underfunding."

[The very limited increase in CCG funding has had] "No impact upon services seen in 2014/15, due to supporting the financial position from reserves, but is very likely to have a negative impact upon services across the hospice in 2015/16, as reserves are reaching a critically low point."

Funding levels/variations

Variation in funding levels remains significant between hospices, both in relation to funding by clinical commissioning groups and local authority commissioners of social care.

Across the sector as a whole the level of statutory funding reported in 2014/15 ranged from 0% (no statutory funding) to more than 50% of care costs being met through CCG funding.



Funding from CCGs continues to represent a relatively modest proportion of children's hospices' total income and the overall costs of delivering care. On average, local CCG funding contributed 10% to the cost of care provided by children's hospices. This has fallen from 12% in 2013/14.

And funding levels across different local areas are inconsistent. Over a third (39%) of CCG funding across England supports just two children's hospices. One hospice receives nothing at all from their CCGs.

NHS England currently provides an annual £11 million grant for children's hospice services in England. Introduced in 2007, it was designed

to address the lack of funding from local commissioners. For the 22 children's hospices which responded to this question in our survey, on average, the grant funds 9% of children's hospices' care costs – a fall from 13% in 2013/14.

Almost all (96%) of children's hospices did not think that funding from their local CCG(s) in 2014/15 was at a level whereby they would not need their NHS England children's hospice grant.

The grant continues to be crucial therefore. Eighty-nine per cent of children's hospices reported that they may be forced to reduce their services if the NHS England grant

stopped. Over half (58%) would reduce short break services, nearly half (46%) would reduce family support and 15% would reduce the amount of end of life care they provide.

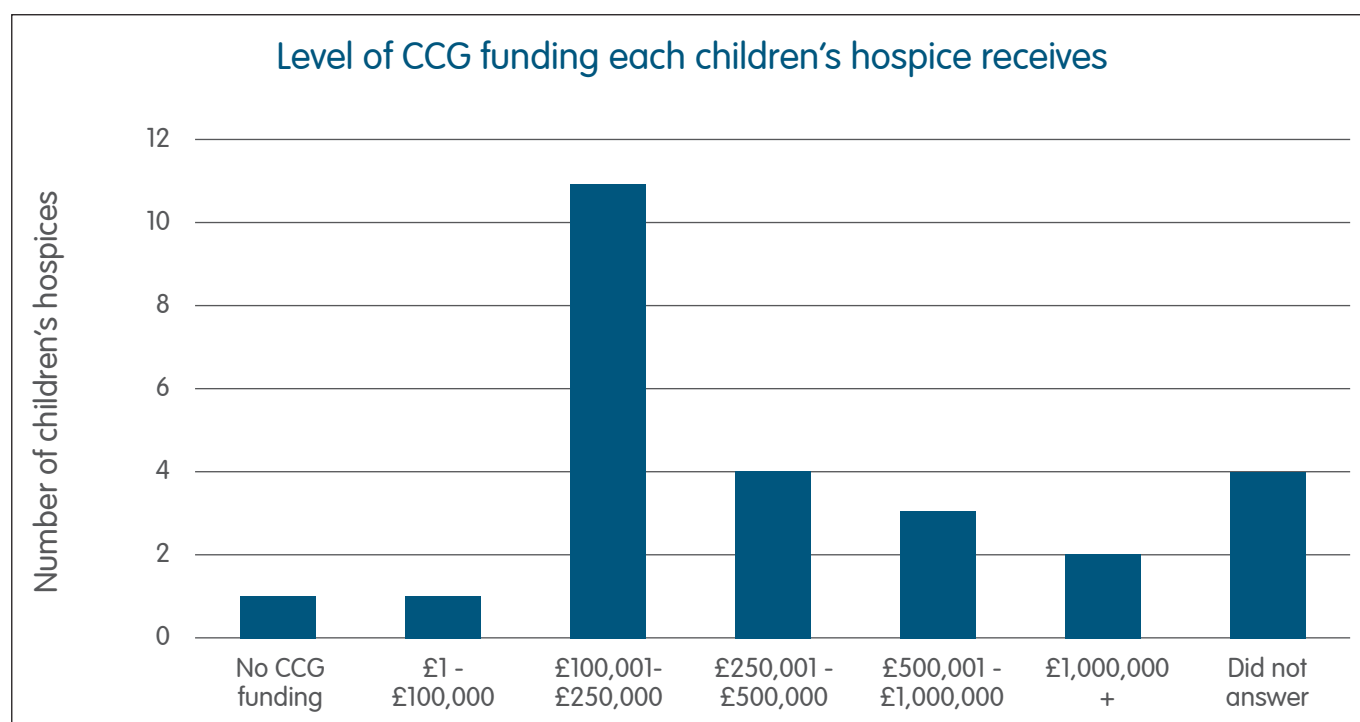
During 2014/15, children with continuing care packages have gained the right to a personal health budget. Children and young people aged 0-25 years with an education, health and care (EHC) plan also now have a right to a personal budget. As a result, 27% of children's hospices received funding from personal budgets during 2014/15 – an increase from 8% in 2013/14. With 31% of children's hospices expecting to receive personal budgets funding in 2015/16. However, personal budgets only accounted for a mean of 1% of children's hospices' care costs.

In contrast, across the whole hospice sector only 8% of hospices surveyed received funding from personal budgets during 2014/15, with 9% expecting to receive such funding during 2015/16. Where hospices received continuing care funding the degree to which that funding met the organisations care costs ranged from under 1% to 50%.

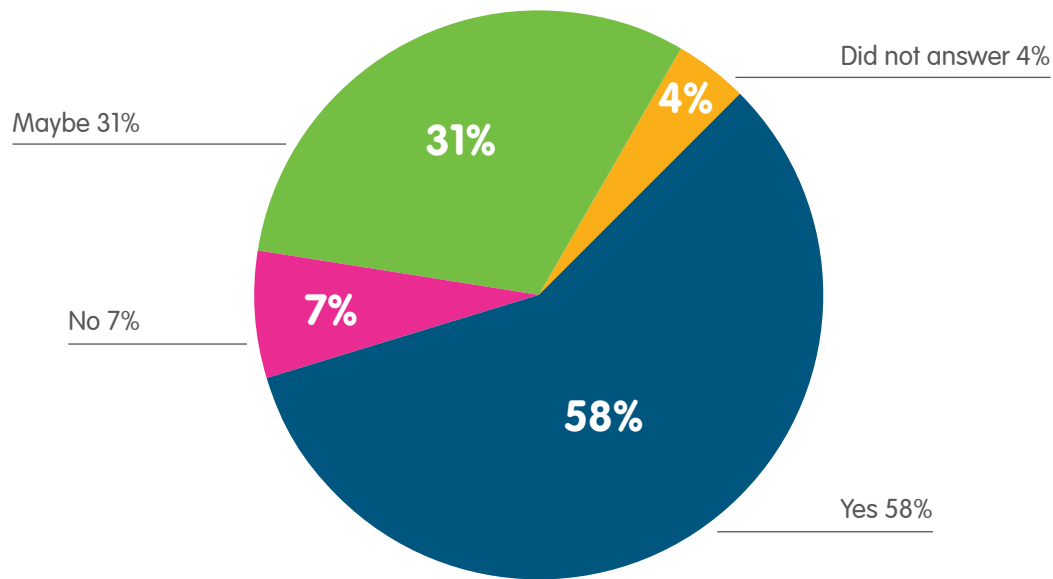
"Standstill budgets mean more voluntary income has to be raised to cover the costs."

"Uncertainty with the children's hospice grant also breeds uncertainty with financial forecast and planning service provision development."

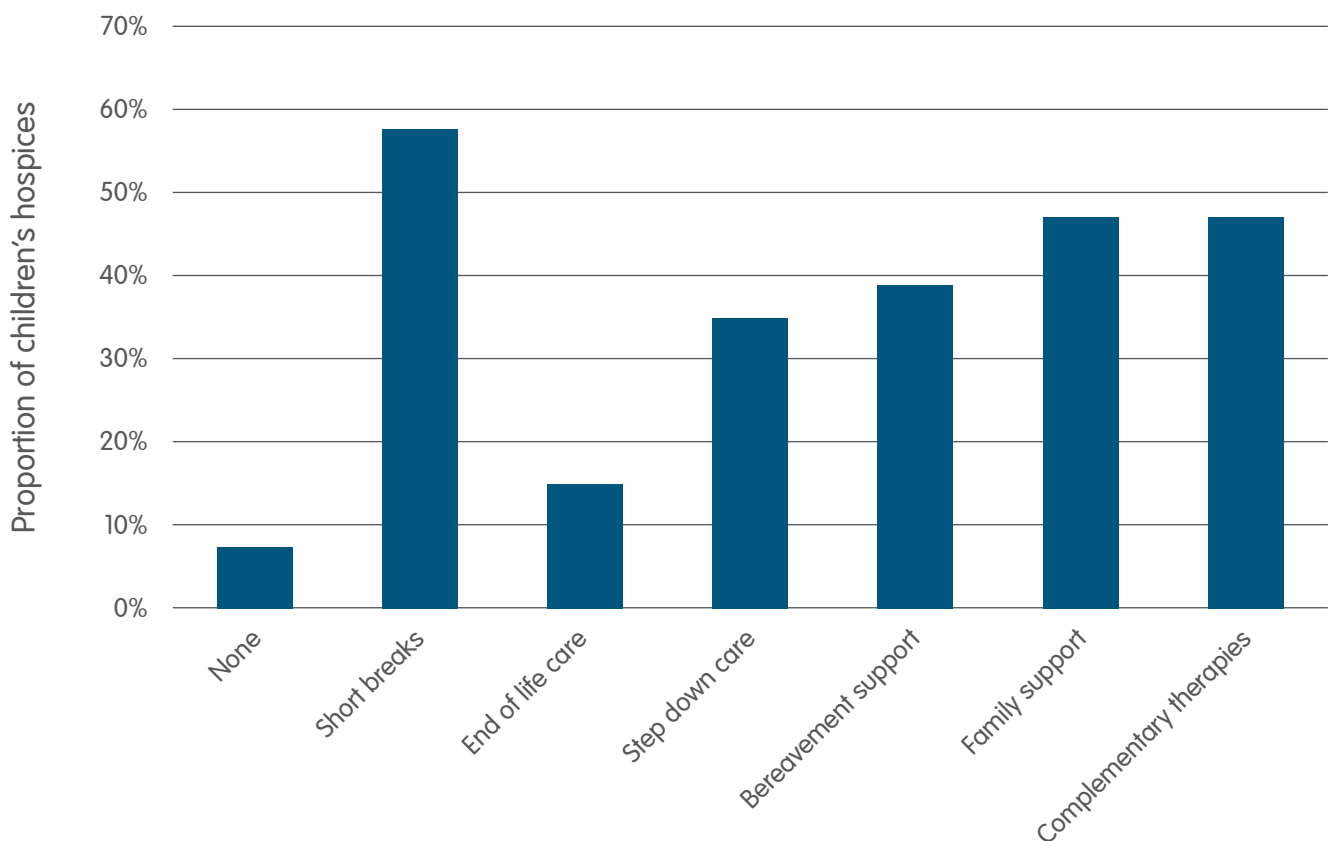
[If the grant had not been available in 2015/16] "Would have needed to actively plan for a reduction in services – likely to be in complementary therapies and family support, with potential to have also affected short-break and/or step-down care."



In the event that the NHS England children's hospice grant was no longer available in 2015/16, would you envisage reducing your services?
(children's hospices surveyed)



If your NHS England children's hospice grant was no longer available in 2015/16, which services, if any, would be reduced?
(children's hospices surveyed)



Funding increases

More encouragingly, almost a third (29%) of hospices surveyed reported an increase in funding from NHS commissioners from 2013/14 to 2014/15. And 22% expect funding to increase in 2015/16.

Twelve per cent of hospices surveyed reported an increase in funding resulting from expansion of existing services and 10% reported an increase as a result of the development of new services.

Thirty-five per cent of children's hospices received more funding from NHS commissioners in 2014/15 than they had in 2013/14. Twelve per cent of children's hospices attributed this to the fact that they had expanded their services. Where children's hospices received an increase in funding from NHS commissioners, the mean increase was £71,000.

Across the sector hospices reported increases in funding ranging from £5,000 to more than £800,000. One hospice saw a 90% increase in funding as a result of working with commissioners to develop and deliver a new fully funded service. In contrast the level of increase for some hospices represented as little as 0.25%

Where significant additional funding was available, hospices reported it delivering benefits for patient care: for example through reducing admissions into acute services for people at the end of life; enabling hospices to provide more care in community based settings; improving coordination of care; and facilitating rapid discharges from hospital enabling improved levels of choice for people at the end of life.

Commissioning arrangements are complex and disproportionate

Hospices continue to face a complex commissioning environment.

Almost half of hospices surveyed work with three or more CCG commissioners and almost a third work with four or more commissioners. One hospice reported working with 23 CCG commissioners.

For children's hospices the position is more complicated as a result of the wider geographical areas they serve. Fifty per cent of children's hospices are working with three or more CCG commissioners, while 46% are working with four or more. Children's hospices are commissioned and funded by a mean of seven local CCGs each.

The number of statutory funding agreements which children's hospices have in place ranges from 0 to 32. For hospices providing services to adults only, the number of agreements ranges from 0 to 12.

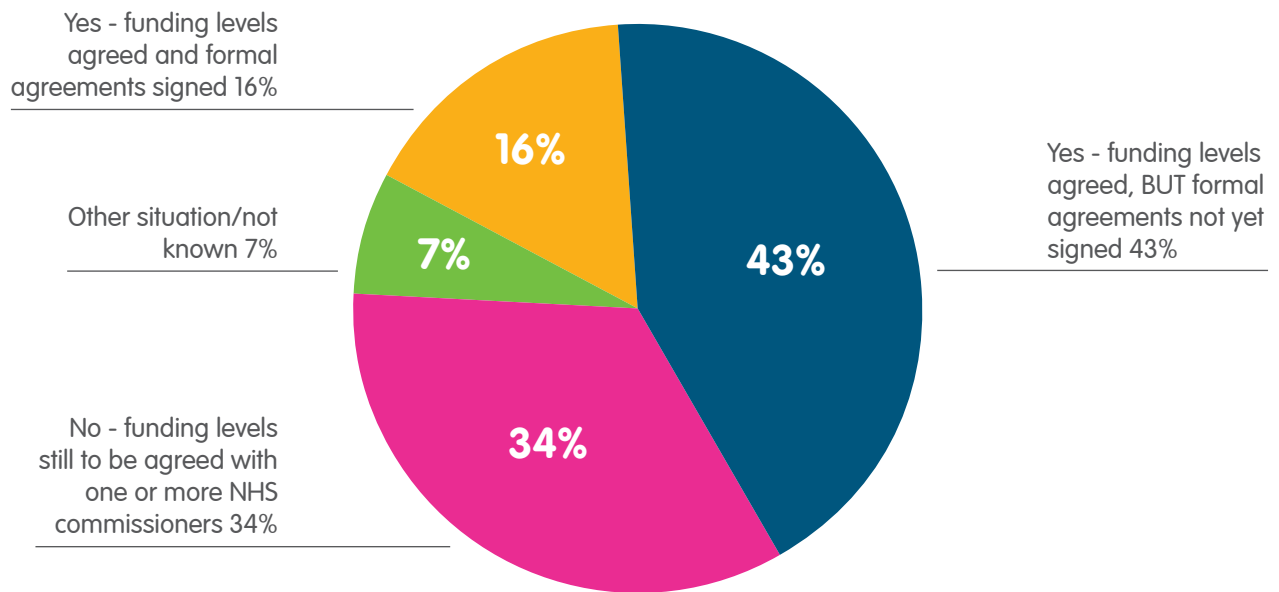
The contracting arrangements with CCG commissioners are becoming more complex for hospices. Over half (53%) of hospices surveyed had at least one NHS standard contract in place in 2014/15. And a quarter of hospices that have a standard contract have three or more contracts in place.

The extent to which the NHS standard contract is used in the hospice sector is a concern – given the extra burden it can place on hospices in comparison to the proportion of care costs met by CCG funding. For children's hospices (which on average receive an even lower contribution to care costs than adult hospices) the disproportionate nature of the contract is even starker. Forty-six per cent of children's hospices report having at least one NHS standard contract in place.

Increasingly hospices are also being involved in competitive tendering for services. Twenty-two per cent of hospices surveyed reported being involved in competitive tendering in the previous 12 months. This figure is up from 16% of hospices in 2014.

Concern also remains for many hospices around the certainty of their statutory funding arrangements. At the time of our survey (April to May 2015) less than a fifth (16%) of hospices surveyed had agreed their funding levels and signed formal agreements. Over a third (34%) of those surveyed had not yet agreed funding levels with one or more of their NHS commissioners.

Progress in CCG funding agreements for 2015/16 (all hospices surveyed)



"We are doing what we can to engage with commissioners but our area covers 17 CCGs and 9 Local Authorities and some are more willing to engage than others."

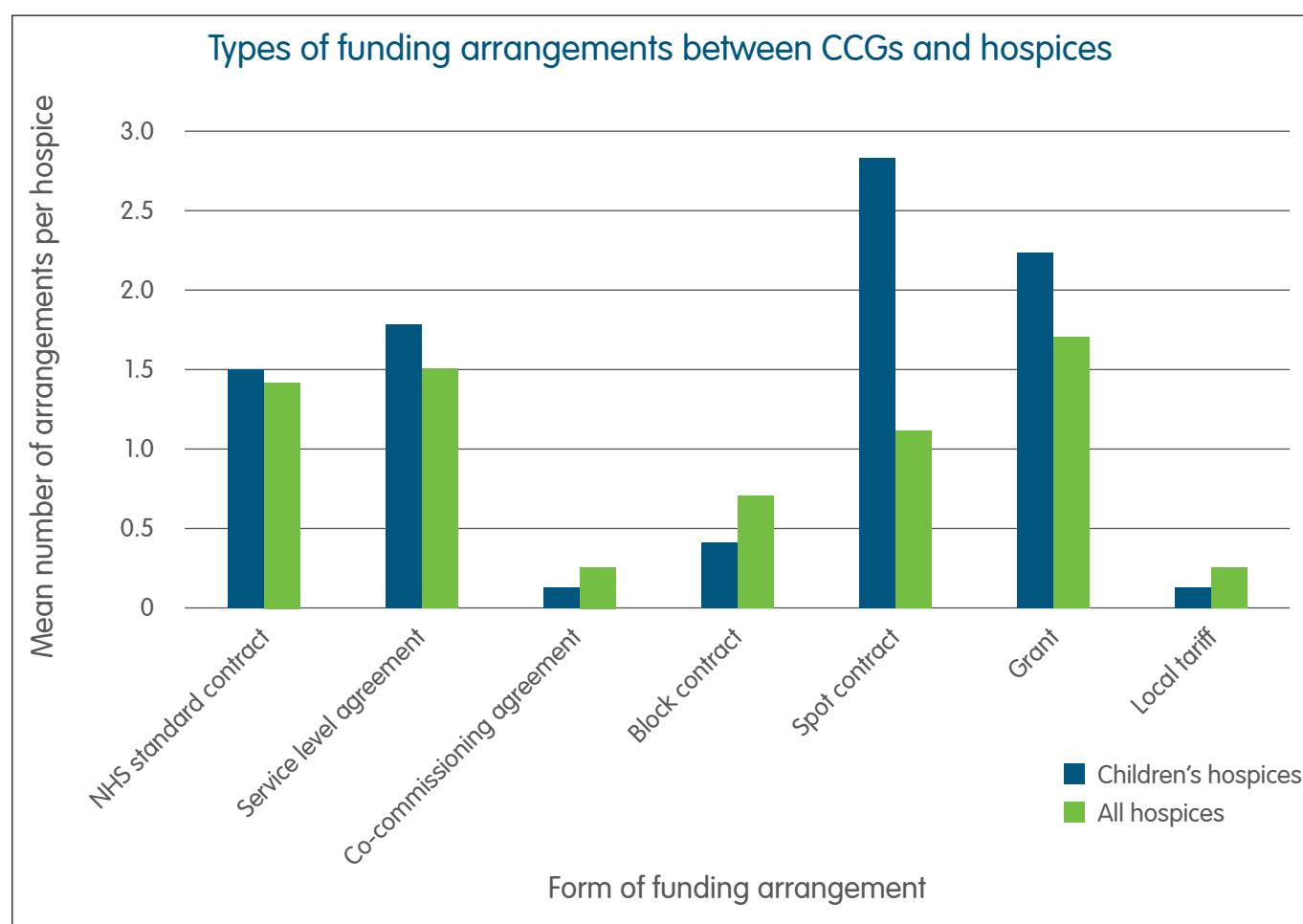
"We recently moved to a standard contract with one of our CCGs which is monitored by a procurement team not the commissioner, we are anxious that this will reduce our relationship. They are also expecting a lot more KPI information which is placing a lot of expectations on the organisation to report with no increased funding to get this information. LA – we have had our funding cut or reduced and there is also uncertainty about. H&WB – we do not currently have a relationship with them; as much as we wished."

Statutory funding across children's hospices is more uncertain than the hospice sector as a whole. Only 26% of all NHS standard contracts run for more than 12 months in the children's hospice sector compared with 42% across all hospices.

Looking to the future development of a new funding mechanism for hospice and palliative care; while 28% of hospices reported an active interest in being involved in the current pilots to develop the palliative care currency a number of hospices reported a lack of confidence or interest in the pilots among CCGs.

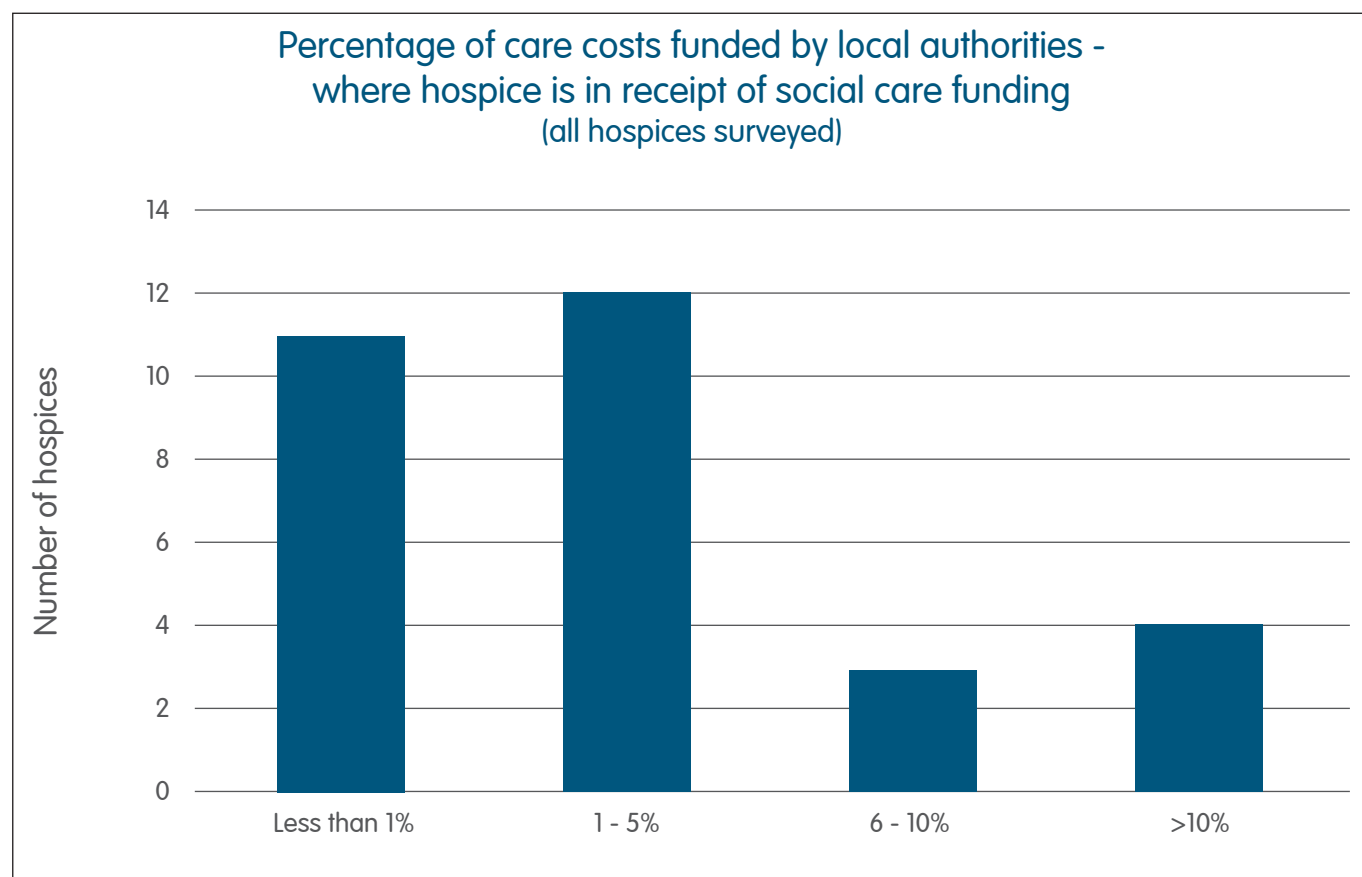
"[The CCG] Have indicated that they think this will be a redundant funding mechanism."

"We have made [the CCG] aware [of the pilots], but frankly they have other 'crocodiles nearer the canoe' and will wait to see what happens after the pilots."



Integration: local authorities, health and wellbeing boards and JSNAs

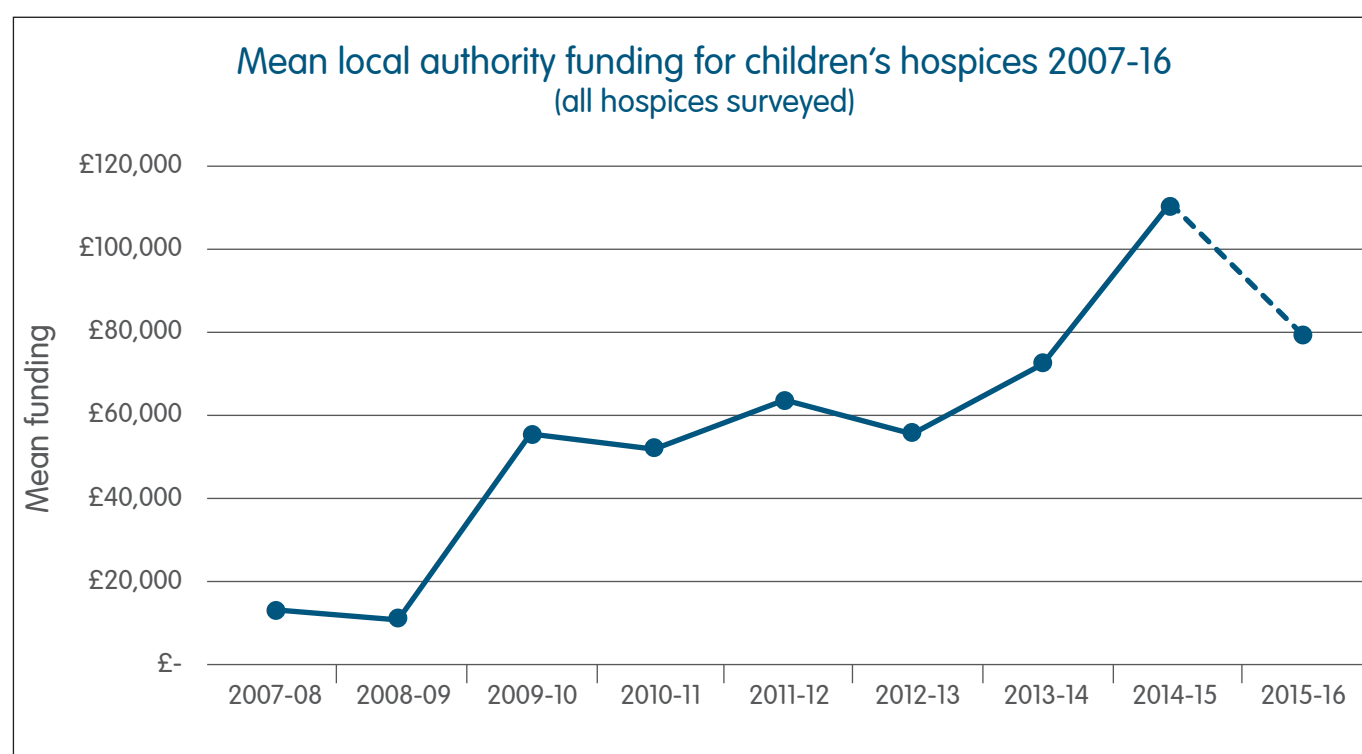
In spite of providing a range of social care services, less than a quarter (23%) of hospices surveyed reported receiving funding from local authorities to fund social care services. Furthermore, where hospices do receive funding from local authorities, variation exists in the levels received.



Among children's hospices 35% of children's hospices received no funding at all from their local authorities in 2014/15 while 26% received over £100,001.

Across the sector as a whole, where local authorities funded social care, the funding represented a mean level of 7% of care costs in 2014/15.¹⁵

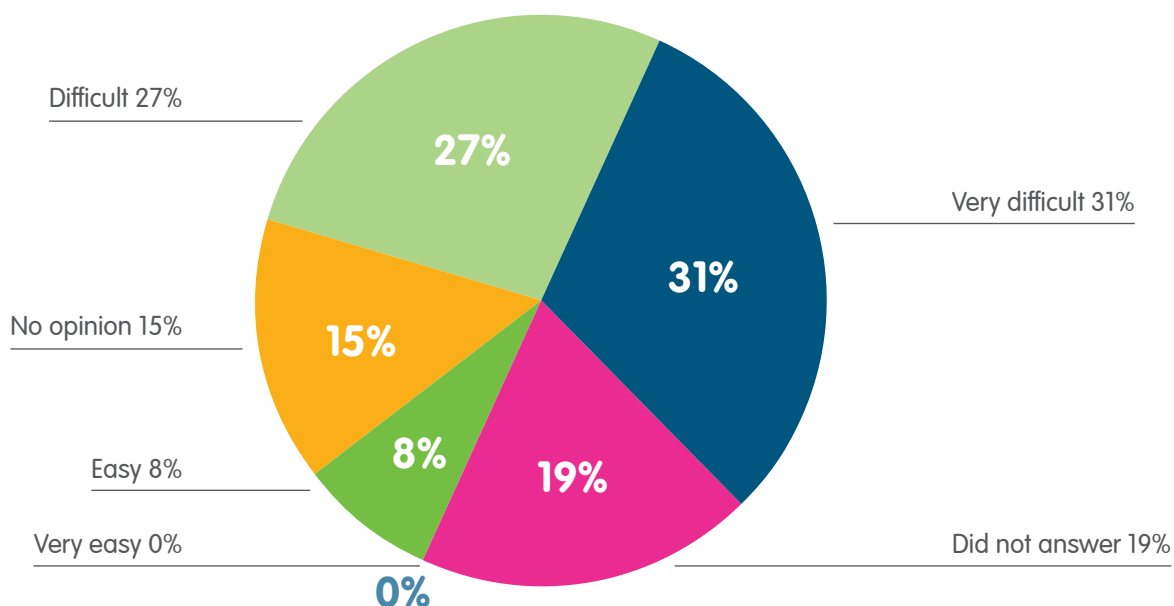
Mean funding per children's hospice has increased by 56% in 2014/15 to £111,000 compared to £71,000 in 2013/14. However, this continues to represent a very modest contribution, only 3% of the average annual cost of care provided by children's hospices. This has been a trend over the last six years, with local authority support remaining broadly static and representing a small part of services' commissioned income.



The majority of children's hospices in England provide short breaks for children and young people with life-limiting and life-threatening conditions. England-wide statutory funding for short breaks began in 2008; in 2010, the coalition government announced £800 million funding over four years for short breaks, to be distributed by local authorities. Since 2011, local authorities have also been duty-bound to provide a range of short breaks to carers of disabled children – and to publish information to parents about what they can access.

Only 8% of children's hospices found it easy to apply to short breaks funding in 2014/15. Over half (58%) found it either difficult or very difficult. This is despite over two-thirds being recognised by their local authorities as a short breaks provider. Children's hospices are commissioned and funded by a mean of three local authorities each.

How easy has it been for your children's hospice to apply for short breaks funding during 2014/15?



Less than half of hospices surveyed (49%) reported having a relationship with local authority commissioners in their areas. Only 11% of hospices surveyed reported that their relationship with local authority commissioners had improved over the past year.

Hospices appear to find it more challenging to engage with parts of the wider health and social care economy. Only 37% of hospices surveyed are currently engaged with their health and wellbeing boards. And fewer still (28%) are currently engaged with public health bodies. The situation appears even more difficult for children's hospices. Only 19% of children's hospices have relationships with their local health and wellbeing boards. The level of engagement between hospices and health and wellbeing boards is disappointing given the important role that these bodies can have in integrating care in local areas.

More encouragingly 95% of hospices surveyed reported being engaged with their local CCGs and 92% being involved with their local hospitals.

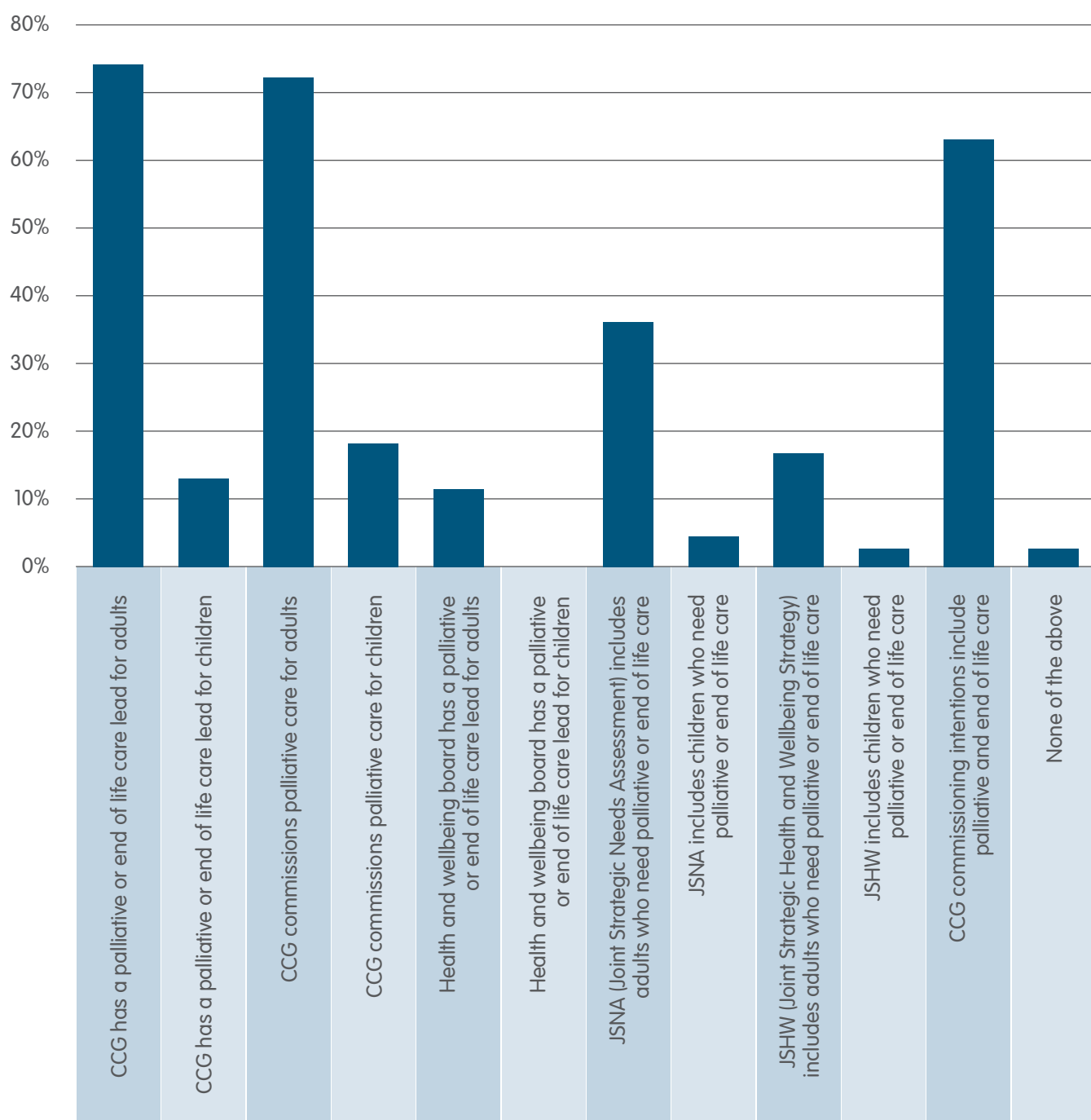
The priority being given to palliative and end of life care also continues to be disappointing. A report by Hospice UK and the National Council for Palliative Care in 2014¹⁶ found that only 43% of health and wellbeing boards had explicitly considered the needs of dying people within their joint health and wellbeing strategies. In this survey, only one in nine hospices (11%) reported their health and wellbeing boards having a palliative or end of life care lead for adults and none reported a lead for children's palliative or end of life care.

Just over a third of hospices (36%) reported that their local joint strategic needs assessments (JSNA's) contained a mention of adults with palliative or end of life care needs, a figure that drops to 4% of hospices reporting that their local JSNA includes children who need palliative or end of life care. This is particularly disappointing given the government's special educational needs and disability (SEND) code of practice states that the JSNA includes specific analysis of the needs of those needing palliative care.¹⁰

"Our total local authority funding makes only a minimal contribution to cost of the care we provide, the majority of which is via individually-negotiated 'spot' agreements."

"One of our local authorities has a long-term contract with a large short breaks provider, which is not yet up for re-tender. The last contract did not separate out palliative care from other residential short breaks. Our commissioner does not appear willing to consider alternative options for providing appropriate short breaks to families of children with palliative care needs."

How is palliative and end of life care prioritised in your local area(s)?



However, the picture varies between localities. Where relationships have developed well, the results have been positive for hospices, and for their commissioners in relation to service delivery.

"CCGs are now starting to consider the hospice as a more significant provider locally. End of life is higher up the local agenda. Openness to a unique joint commissioning arrangement very welcome."

Working together

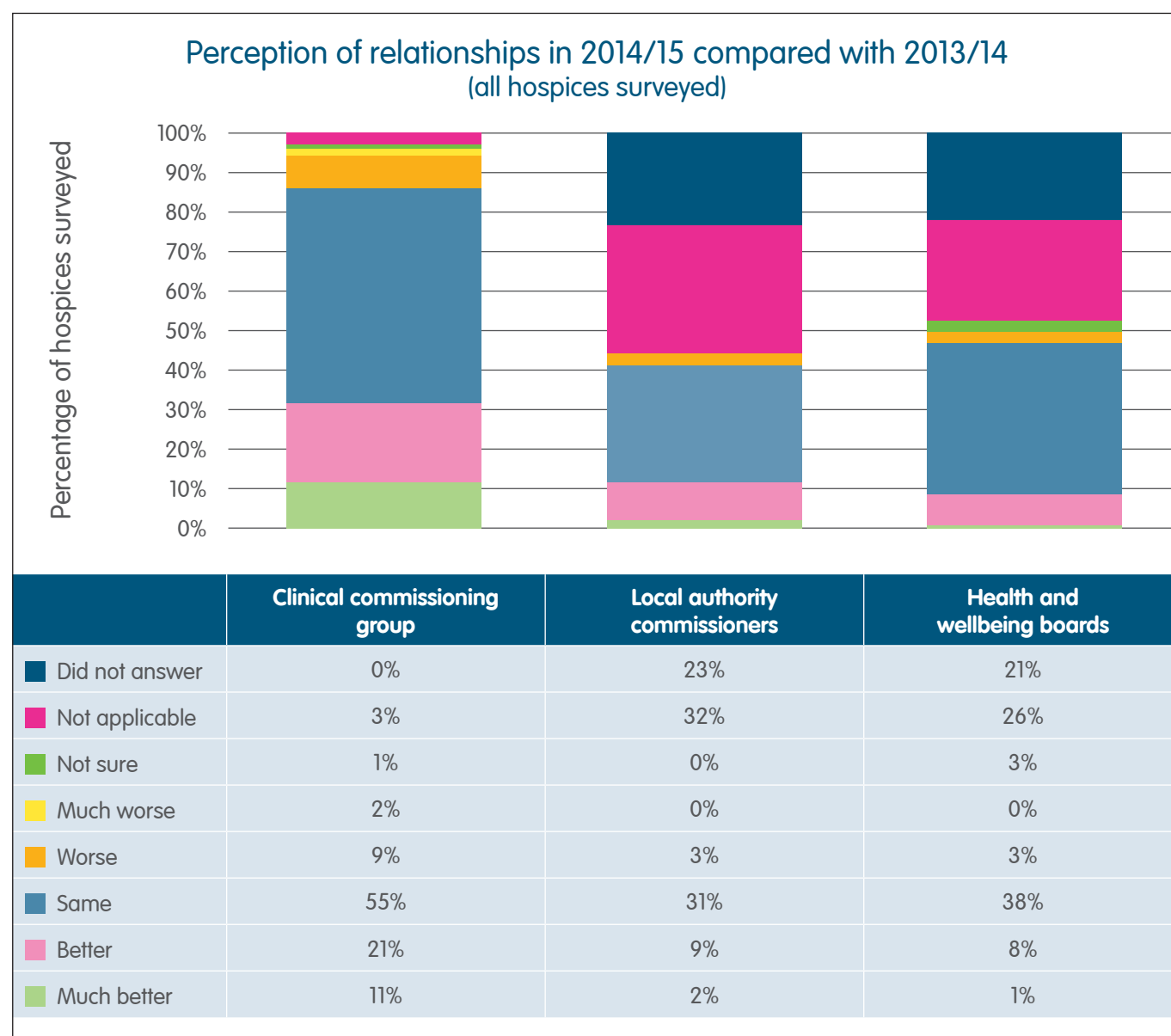
As both major funders and providers of care and also organisations embedded in their local communities, hospices can be good partners to commissioners in developing and delivering integrated services to their communities.

However, the extent to which commissioners and hospices are engaging across England is patchy. Hospices report improvement in some areas but overall the picture has remained relatively static over the past year.

Under half (42%) of children's hospice respondents state that their local CCGs commission children's palliative care.

This suggests that in some areas, while children's palliative care may be being provided by a range of different services (including children's hospices), CCGs may be failing to take action to fully understand what children's palliative care is needed or commission this care in a joined up way.

Across the sector 32% of hospices felt that their relationships with CCGs were better or much better over the past year, with 55% reporting no change. Eleven per cent of hospices surveyed reported improved relationships with local authority commissioners while 31% reported relationships remaining the same.

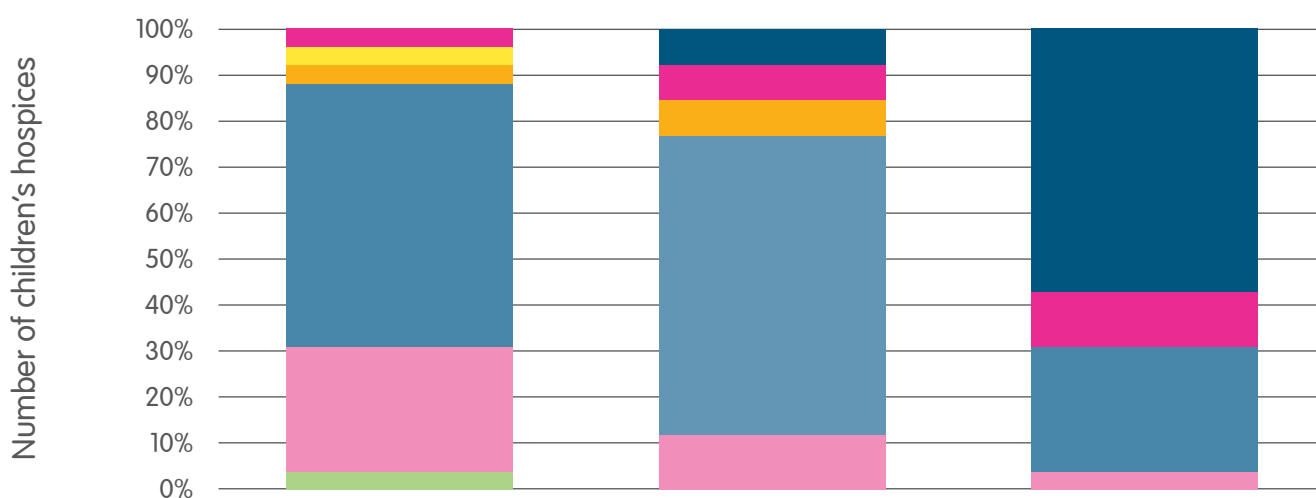


A similar picture is reflected among children's hospices.

Comparing 2013/14 to 2014/15, only 8% of children's hospices felt that their relationships with NHS commissioners were worse or much worse. Thirty-one per cent thought that they were better or much better, while 58% thought they were the same.

Comparing 2013/14 to 2014/15, a majority of children's hospices who reported having relationships with local authority commissioners reported that the relationship was better (15%) or the same (62%).

Children's hospices' relationships with commissioners and other key stakeholders during 2014/2015 overall compared with 2013/14



	Clinical commissioning groups	Local authority commissioners	Health and wellbeing boards
Did not answer	0%	8%	58%
Not applicable	4%	8%	12%
Not sure	0%	0%	0%
Much worse	4%	0%	0%
Worse	4%	8%	0%
Same	58%	62%	27%
Better	27%	15%	4%
Much better	4%	0%	0%

For many hospices, it remains a struggle to engage:

"Those commissioners who constructively engage continue to do so; those who don't, don't! Without any levers for commissioners to engage with us – or a change of ethos – it is hard to make in-roads. Despite our own efforts and encouragements from both the Strategic Clinical Network and a local MP, engagement in meaningful dialogue with our most local commissioner remains a challenge."

"CSU is notoriously difficult to work with: much confusion as to who does what or who should do what. CCGs are very much a mixed situation, ranging from some straightforward relationships which work well and are of benefit to children and families, to some very complicated and difficult relationships."

"We have tried, without success, to engage with (our local CCGs in a particular county) – and even included local MPs with this activity...they continually rebuff approaches, even after including their CEO in discussions."

"Relationships are improving but it is hard work mostly due to NHS systems and processes that do not make it easy for voluntary sector involvement... [We] have to fight hard to stay at the table whereas previously we were recognised in our own right as experts in our field regarding the management of palliative patients."

However, while it is clear that some hospices are finding the statutory funding environment more difficult, other hospices are experiencing very positive relationships with their commissioners.

Overall there are some good examples of hospices forming positive relationships with local statutory organisations:

From among children's hospices:

"We engage with the CCGs, CSUs and LA commissioners regarding funding on behalf of the children's hospice organisation. We have an established working relationship in local areas and commissioning arrangements that support the children's hospice organisation to manage our own caseload. However, we seek to improve our relationships and funding agreements with those CCGs that are not immediately local but have a cohort of children from that area who attend the children's hospice organisation without any statutory financial support. We engage with Healthwatch and health and wellbeing boards occasionally, but need to further develop these relationships.

In our previous engagement with these bodies we found them more focused on adult care, despite having a remit for children's services. Our clinical teams are part of local clinical networks. They also have relationships with individual GPs and local hospitals, although we have more contact with the community children's nursing teams than GPs, because our caseload is more regularly cared for in the community than through primary care. We are always looking for ways to improve our local relationships and this includes the Clinical Senates, the LETBs and the Local Area Teams for NHS England in the future."

From among adult hospices:

"I am the current lead for the end of life workstream for the local health and social care community in [the locality]. This is part of the integrated care development work plan and is all about the shift of activity and funding from acute to community ... We have four specialist nurses based at the acute hospital that the hospice funds. Additionally, our consultants are employed by the local Acute [trust] ... The hospital also allows us to promote our services and fundraising on their site. Our clinical director and two consultants are linked in to the clinical networks locally. LA commissioners are part of the EoL project I am leading so we are building relationships there via this project."

"Our experience is that the more people understand what we are doing (including that it keeps or gets end of life patients out of hospital) the more supportive they are. So GPs and hospitals are supportive and work well with us."

Terminology

Palliative care

The World Health Organization provides definitions of palliative care for adults and children at www.who.int/cancer/palliative/definition/en (reproduced below):

“Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patients illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Hospice care

The Commission into the Future of Hospice Care 2013¹⁷ defined hospice care as:

“Palliative and end of life care provided by hospices for people of all ages with life-shortening illnesses, their relatives and family carers. It is delivered in partnership with others, including local communities, so as to reach out to more of those who could benefit from it, and into the many different settings where care is needed. It is a dynamic and innovative response by hospices, which are constantly adapting to meet the palliative and end of life care needs of the communities they serve. Hospice care is about dying, death and bereavement and about living with these realities.”

For more information visit the Hospice UK website: www.hospiceuk.org

Children's palliative care

Children and young people with life-limiting and life-threatening conditions need palliative care. Life-limiting conditions are those for which there is no reasonable hope of cure and from which children are expected to die. Life-threatening conditions or events are those for which curative treatment may be feasible but can fail. Life-limiting and life-threatening conditions in children and young people can be defined by the four categories set out in Together for Short Lives' Core Care Pathway.¹⁸

Together for Short Lives defines children's palliative care as¹⁹:

- an active and total approach to care, from the point at which a child is diagnosed with – or recognised as having – a life-limiting or life-threatening condition; this is often from birth
- provided throughout the child's life, death and beyond
- embracing physical, emotional, social and spiritual elements – and focusing on enhancing the quality of life for the child or young person
- including support for the family
- managing distressing symptoms
- providing short breaks
- providing care through death and bereavement.

Children's hospice care

Together for Short Lives defines children's hospice care as¹⁹:

- providing palliative care for children and young people with life-limiting conditions and their families
- delivered by a multi-disciplinary team and in partnership with other agencies
- a holistic approach to care, aiming to meet the needs of both the child and their family – physical, emotional, social and spiritual.

For more information visit the Together for Short Lives website: www.togetherforshortlives.org.uk

End of life

The Leadership Alliance for the Care of Dying People defined end of life as follows²⁰:

Patients are 'approaching the end of life' when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with:

- advanced, progressive, incurable conditions
- general frailty and co-existing conditions that mean they are expected to die within 12 months
- existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- life-threatening acute conditions caused by sudden catastrophic events.

In General Medical Council guidance the term 'approaching the end of life' also applies to those extremely premature neonates whose prospects for survival are known to be very poor, and to patients who are diagnosed as being in a persistent vegetative state (PVS) for whom a decision to withdraw treatment may lead to their death.

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- ⁷ In 2010, the government published the Coalition Programme for Government. The programme included a commitment to introduce a new funding system for hospice and palliative care in England.
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- ⁹ Because hospices provide holistic models of care which span health, social care and other types of service, they can be funded by a variety of different national and local commissioners; often, these different commissioning arrangements do not join up, causing gaps in commissioning and misunderstandings as to which organisation should be funding what – often around bereavement care, short breaks and specialised services.
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About Hospice UK and Together for Short Lives

Hospice UK

Hospice UK is the national charity for hospice care. We champion and support the work of more than 200 member organisations, which provide hospice care across the UK, so that they can deliver the highest quality of care to people with terminal or life-limiting conditions, and support their families.

Hospice UK supports the breadth, dynamism and flexibility of modern hospice care by: influencing government and decision makers; improving quality of care through the sharing of good practice; and providing training, education and grant programmes.

We work collaboratively with our members to support their vital work and to create a stronger voice for hospice care in the UK. We also support the development of hospice and palliative care worldwide.

For further information visit our website:
www.hospiceuk.org

Together for Short Lives

Together for Short Lives is the leading charity for UK children's palliative care. We support those who help, love and care for children and young people who are unlikely to reach adulthood.

We work with children's hospices and a range of other services across the country to ensure that every child, young person and their family has the best possible care and support whenever and wherever they need it. From the moment of diagnosis, for whatever life holds, we help to ensure families make the most of their precious time together.

Visit www.togetherforshortlives.org.uk for more information.



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