



On the brink: a crisis in children's palliative care funding in England

The results of Together for Short Lives and Hospice UK's survey on children's palliative care funding and commissioning in England 2015/16

#fundnotfail

November 2016

Introduction

1. UK children's charity, Together for Short Lives, together with Hospice UK, have asked charities providing hospice and palliative care in England to tell us how much statutory money they receive. For voluntary sector providers of children's palliative care services (referred to hereafter in this report as 'charities'), our survey looked at three main types of funding including:
 - a. the NHS England children's hospice grant
 - b. funding from NHS clinical commissioning groups (CCGs)
 - c. funding from local authorities.
2. Our survey was based on the statutory funding they received in 2015/16.
3. We have carried out the same survey with these charities for eight years so we can understand funding trends and their impact on services for children with life-limiting or life-threatening conditions. We asked those charities which provide health or social care to children and young people.
4. 27 charities responded to our survey. Of these, 26 provide healthcare to children and young people with life-limiting or life-threatening conditions and could reasonably expect to be commissioned and funded by CCGs. All 27 of the charities provide social care to this group of children and young people and could reasonably expect to be commissioned and funded by local authorities.
5. Together for Short Lives has 36 charity members, including children's hospice charities, which provide healthcare to children and young people in England with life-limiting and life-threatening conditions. The response rate to this survey from healthcare-providing children's palliative care charities is therefore 72%.
6. Together for Short Lives has 37 charity members which are regulated by the Care Quality Commission and provide social care to children and young people in England with life-limiting or life-threatening conditions. The response rate to this survey from social care-providing children's palliative care charities is therefore 73%.

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Executive summary

1. The number of babies, children and young people with life-limiting or life-threatening conditions is increasing and the demand for services is growing.

As care becomes more complex, the cost of care is rising

- There are 40,000 (aged 0-19) babies, children and young people with life-limiting or life-threatening conditions in England alone (compared to 30,000 in 2000/01). We know that the number of babies, children and young people with life-limiting or life-threatening conditions is rising. The highest rate of increase in this period is among those aged 16-19 years.
- Medical advances mean that more premature babies with complex medical conditions are surviving. And medical developments are helping more children to live longer with many living well in to their adulthood. Many of these babies, children and young adults have very complex conditions and need 24/7 care.
- The cost of caring for an increased number with complex medical needs is rising and services need to respond and extend their services to meet the growing demand.
- The cost of care provided by children's palliative care charities is increasing and is now 9.7% greater in real terms in 2015/16 compared to 2014/15.
- State funding is not keeping pace with demand; in fact it's declining.

2. Statutory funding for children's palliative care charities in England is declining

- State funding for children's palliative care charities is declining in year on year and becoming more variable. It's a worrying trend.
- **Overall, the state's contribution to the money which charities need to provide children's palliative care fell to 22% in 2015/16 compared to 23% in 2014/15 and 27% in 2013/14.**
- And statutory funding for children's palliative care charities is inequitable compared to that for adults. Adult palliative care charities are valued more highly by the NHS and local authorities compared to children's palliative care charities; adult charities receive a 30% of their costs from statutory funding compared to the 22% received by children's charities.
- Charities delivering essential children's palliative care to children and families in England have an insecure funding future. And there is little evidence so far to suggest that the new NHS children's palliative care funding currency will change this.

3. The future for families of seriously ill children looks bleak

- Charities say they will be forced to cut essential services if state funding continues to decline. Funding cuts and freezes across England mean that children's palliative care services are not able to expand to meet the needs of the growing number of children and young people with life limiting or life-threatening conditions.

- Without the support of children's palliative care charities, it is likely that more families are being plunged into crisis, putting ever more pressure on already stretched emergency services. It's make or break.

4. Statutory funding for children's palliative care charities in England is patchy

- The survey also reveals a children's palliative care funding postcode lottery. The amount of money given by the state to children's palliative care charities varies considerably. There's a gulf in funding, depending on where a charity is based. The difference in funding is staggering.
- When taking the NHS Children's Hospice Grant and funding from clinical commissioning groups and local authorities into account, the standard deviation in the state's contribution to children's palliative care charities has risen from 12% in 2015/16 compared to 10% in 2014/15.
- The range of statutory contributions to charities is huge: one charity receives 53% of the money it needs to deliver children's palliative care from the state, while one receives as little as 2%.

5. Short breaks are essential to families and local authorities have a duty to make sure they are provided to disabled children. Yet local authorities have cut funding for children's palliative care charities.

- Where families are caring for a child with a life-limiting or life-threatening condition and providing around the clock care, relationships often suffer, with 36% experiencing a breakdown of the family¹.
- Short breaks are essential to relieve some of the pressures on families of children with life-limiting or life-threatening conditions. Free from being responsible for providing around the clock care for a few hours or days, short breaks give parents a chance to recharge their batteries, make memories with their seriously ill child or spend more time with their siblings.
- For children and young people with life-limiting or life-threatening conditions, short breaks give them an important opportunity to be with their peers and be more independent.
- This lack of funding is having a direct impact on families. Providing vital respite and support that in the long term saves the state money by reducing the number of hospital visits as well the incidence of family breakdown.
- The mean funding given to each charity by local authorities fell by 61% between 2014/15 and 2015/16. This means that local authorities are only contributing 1% of the money charities need to deliver children's palliative care.

¹ Steele R. (2000) Trajectory of certain death at an unknown time: children with neurodegenerative LTC illnesses. *Cancer Journal of Nursing Research* 32, 49-67.

6. Over half of charities would have to cut services if the children's hospice grant was removed

- Children's palliative care charities rely on the NHS England Children Hospice Grant to deliver essential services to children with life-limiting and life-threatening conditions and their families.
- Without this funding, children's hospices would have no choice - they would have to cut services.
- It's crucial that we work closely with NHS England on to develop a model which brings about sustainable funding for children's palliative care for the long-term - so that children's palliative care charities are there today and tomorrow.
- **Nearly 60% (59%) say they would be forced to reduce their services if the children's hospice grant was no longer available.**
- **Over two thirds (70%) would be most likely to cut short breaks - leaving families at breaking point.**
- **41% would cut bereavement support.**
37% would cut family support services, complementary therapies and day services/outpatient clinics.
- Together for Short Lives is calling on the government to increase the children's hospice grant as a matter of urgency.

7. Scotland has got it right - we need parity for seriously ill children all over the UK

- For families caring for a seriously ill child with a life-limiting and life-threatening condition, it shouldn't matter where they live. But right now, we are worried that cuts to children's palliative charity funding in England could have a devastating impact on children and families living here.
- It's brilliant news that things are much brighter in Scotland - there's a genuine partnership between the Scottish Government and Scottish public to make sure that palliative care for children is funded equitably and sustainably. The Scottish Government has committed £30 million funding for CHAS as part of increased investment in children's palliative care over the next five years.
- But in England it's still the case that hospices and other children's palliative care charities have to fundraise for nearly 80% of their costs - and that time spent raising money could be put to much better use in delivering care to children instead.
- We urge governments in Westminster, Northern Ireland and Wales to take heed of this investment and re-examine their own funding arrangements for children's palliative care charities, which fall far short of the level of investment now provided by the Scottish Government.

8. We can stop the children's palliative care funding crisis

- If we act now, we can do something to avert the crisis in children's palliative care funding.

- But change needs to come today – before charities make cuts to vital services. Families haven't got time to wait.

9. We also need parity with adult services

- People are always shocked to hear that children's hospice and palliative care charities need to fundraise for nearly 80% of the costs involved in delivering vital care to children and families.
- It's even more shocking to learn that children's palliative care charities valued less than adult palliative care and receive nearly 10% less statutory funding.
- Our survey found that adult palliative care charities receive a 30% of their costs from statutory funding compared to the 22% received by children's charities. This makes no sense - palliative care for children and adults should be of equal value to the state.

What we want to happen as a result of our findings

We can change this and create a secure future for children and families:

1. **Implement the national choice commitment:** We would like the government to work with us to implement its recent national choice commitment on end of life care, which states "to support high quality personalised care for children and young people, commissioners and providers of services must prioritise children's palliative care in their strategic planning; this is so that services can work together seamlessly and advance care planning can be shared and acted upon."
2. **A ministerial mandate for joint commissioning:** We would like government to encourage the use of our joint commissioning guidance, and to require CCGs and local authorities to transparently report on their support for children's palliative care and to tackle those that are failing to meet their duty to commission these services jointly; a ministerial mandate would send a powerful signal about its importance.
3. **Provide clarity over responsibilities and guide commissioners on how to apply new models of funding:** We would like the government and NHS England to urgently write to CCGs and local authorities to make clear which parts of the health and care system in England are responsible for commissioning palliative care for children and young people aged 0 – 25. This communication should set out the difference between specialised and general children's palliative care and also promote our joint commissioning guidance. NHS England and the local government sector should work with us to help guide CCGs and local authorities on how to use the currency and other new funding models.
4. **Implement our joint commissioning guide:** We would like CCGs and local authorities to implement [Together for Short Lives' guide to jointly commissioning palliative care for children and young people aged 0 – 25](#), which was funded by the Department for Education. This sets out all the steps that they should take for each stage of the joint commissioning cycle. We make an open offer to help commissioners to do this.
5. **Increase the children's hospice grant:** We would like the government and NHS England to maintain and increase the value of the children's hospice grant to reflect the

fact that demand for this care is increasing and life-limiting conditions are becoming more complex.

6. **Commit to a national children's palliative care inquiry:** Government should commit to a national inquiry, producing a children's palliative care strategy that takes a family centred and holistic approach to health, social care and educational interventions.
7. **Sustainability and transformation plans (STPs) should include children's palliative care:** STPs are an excellent opportunity for CCGs and local authorities to work together to create the economies of scale necessary for commissioning children's palliative care.
8. **We can all help to make statutory funding more equitable and more sustainable:** We would like the public and Parliamentarians to find out how their local CCGs and local authorities are performing by contacting their local VCS children's palliative care organisations. We would like them to ask their CCGs and local authorities what steps they will take to address the gaps in funding highlighted by our survey.

Funding in 2015/16

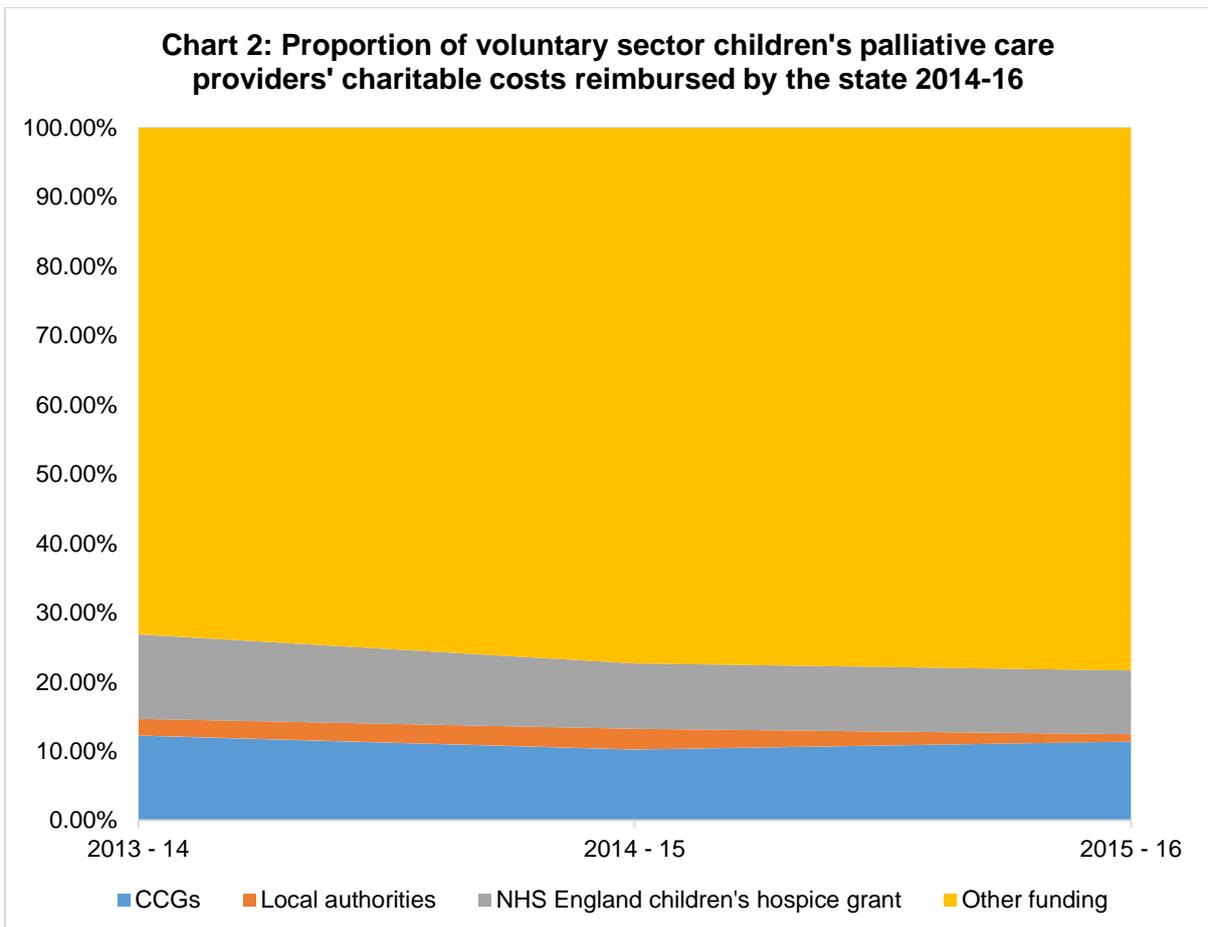
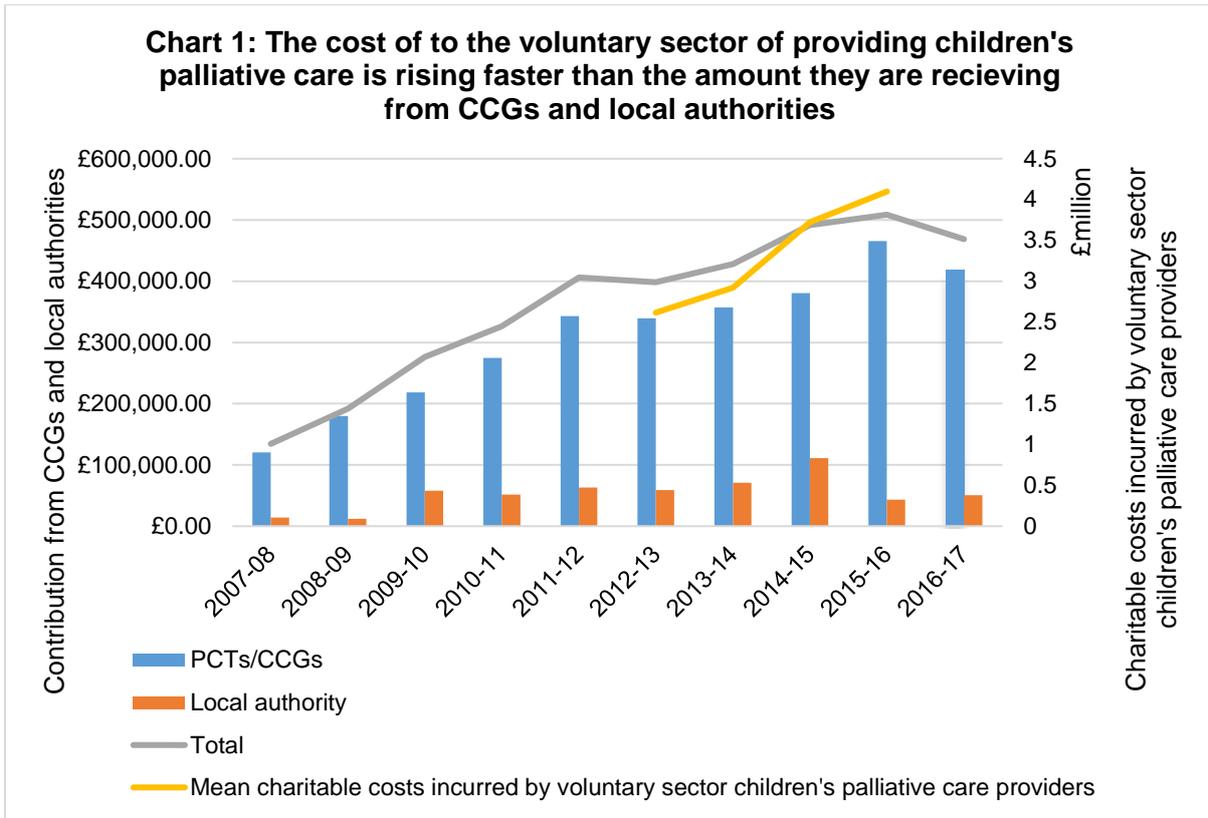
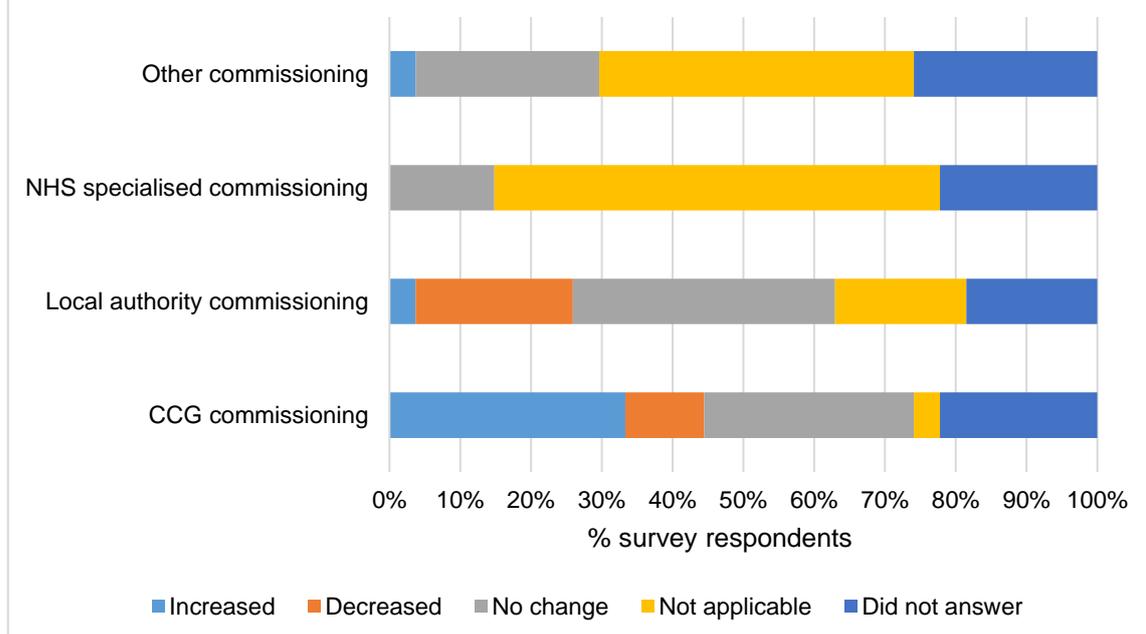


Chart 3: How the level of funding received by VCS organisations from statutory sources in 2015/16 changed compared to 2014/15



As the complexity and demand for care from children and young people becomes greater, charities are spending more on providing care to children and young people

1. As shown in Chart 1, in total the charities which provided data on the statutory funding they receive incurred £84,722,385 in charitable expenditure in 2015/16, which is a mean of £4,034,399 per organisation. This is an increase of 10% on the mean figure reported in 2014/15 (£3,721,083.91). This represents a 9.7% increase in real terms².
2. Demand is increasing for children’s palliative care. 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 care³. 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.

CCGs’ contribution to the cost of providing children’s palliative care in the voluntary sector has increased modestly from 10% to 11%

3. The 20 charities which provided data on their CCG funding received a total of £9.3million in 2015/16. As shown in Chart 1, this means that each charity received a mean of £465,500 from their local CCGs. This is an increase of 22% compared to 2014/15, when the mean was £380,639.59 per charity.

² The consumer price index (CPI) measure of inflation was 0.3% in April 2016 <http://bit.ly/2ckWBdE>
³ Fraser LK, Parslow RC, McKinney PA, Miller M, Aldridge JM, Hain R, Norman P (2012) *Life-limiting and life-threatening conditions in children and young people in the United Kingdom; final report for Together for Short Lives*. Available to download from: <http://bit.ly/1z24ZQw>

4. As shown in Chart 2, this means that, on average, CCGs contributed 11% to the charitable costs incurred by charities in 2015/16, a modest increase from the 10% reported in 2014/15.
5. As shown in Chart 3, 41% of charities reported that their CCG funding was cut (11%) or frozen (30%) between 2014/15 and 2015/16. This is a smaller proportion, however, than the 58% which told us that their CCGs had frozen (35%) or cut (23%) between 2013/14 and 2014/15.
6. Only a third of respondents (33%) reported that their CCG funding had increased between 2014/15 and 2015/16. This is broadly similar to the proportion which reported an increase (35%) between 2013/14 and 2014/15.
7. Of the charities which said that they had received more CCG funding in 2015/16, the mean increase reported was £54,347. The mean decrease reported by those charities which had their CCG funding cut was £53,248.

But local authorities' contribution to the cost of providing children's palliative care in the voluntary sector has fallen significantly by 61%

8. The 21 charities which provided data on their local authority funding received a total of £905,000 in 2015/16. As shown in Chart 1, this is a mean of £43,095 per organisation. This is a dramatic fall of 61% compared to 2014/15, when the mean was £110,909 per organisation.

This means that local authorities contribute just 1% to the charitable costs incurred by VCS children's palliative care organisations

9. As shown in Chart 2, this means that, on average, local authorities contributed just 1% to the charitable costs incurred by charities in 2015/16, a fall compared to the 3% reported in 2014/15.
10. As shown in Chart 3, over half (59%) of charities reported that their local authority funding was cut (22%) or was frozen (37%) between 2014/15 and 2015/16. Only 4% reported that they had increased over the same period. This is a significant change compared to the period 2013/14 to 2015/16, when 23% of charities reported an increase. 54% told us that their local authority funding had been cut (35%) or frozen (19%) in the period 2013/14 to 2015/16.

Overall, the state's contribution to the cost of providing children's palliative care in the voluntary sector fell to 22% in 2015/16 compared to 27% in 2013/14

11. As chart 3 shows, when taking the NHS children's hospice grant received by the charities which responded to the survey into account in addition to CCG and local authority funding, the overall state contribution has continued to fall. It was 22% in 2015/16 compared to 23% in 2014/15 and 27% in 2013/14. The states' contribution to children's palliative care charities is therefore lower than its contribution to adult hospices, which is 33% of charitable costs.

Impact of current funding environment: most charities report that CCG funding is not meeting the rising demand for children's palliative care

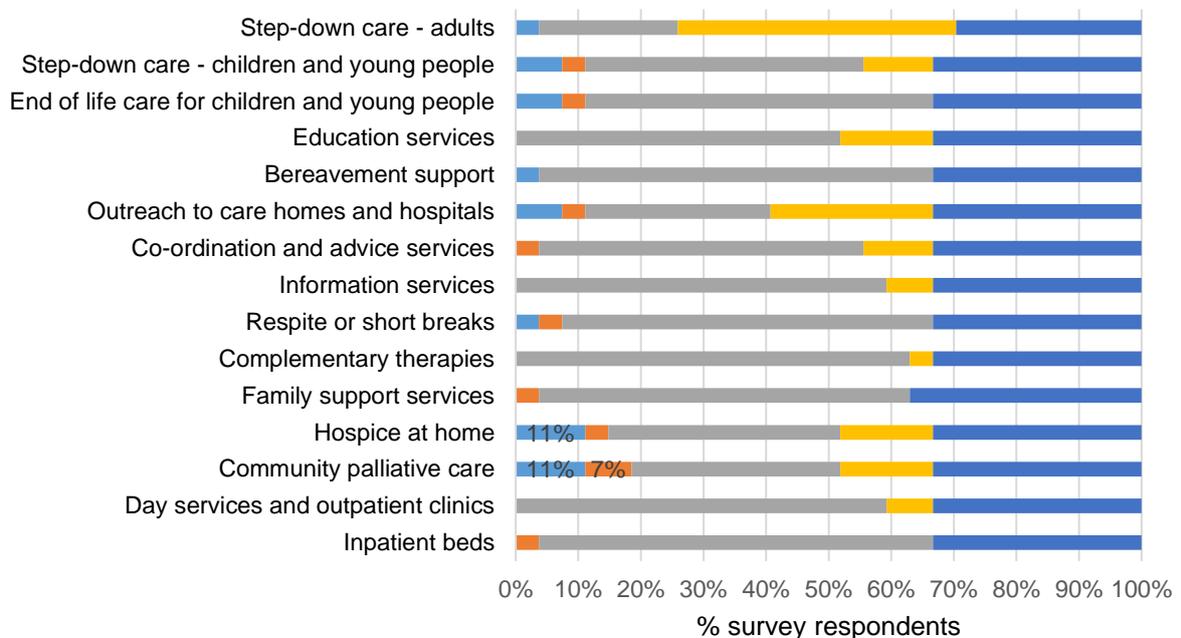
12. As shown in Chart 4 below, 11% of charities have said that where they received more funding from their CCGs, it enabled them to increase the number of children

and young people they could support through community palliative care. 11% also reported an increase in the hospice at home care they could provide.

13. 7% report that where their CCG funding fell, this reduced the number of children and young people they could support through community palliative care.

14. Most providers, however, told us that CCG funding did not change to an extent where they could increase, or were forced to decrease, the number of children and young people who could access their services. While this suggests that the number of children and young people who were able to access children’s palliative care was not falling as a result of CCG funding, it also shows that, worryingly, charities were unable to extend their services to meet the growing demand for them.

Chart 4: The extent to which CCG funding levels are having an impact on the services which VCS organisations provide



- Positive impact (eg increased numbers of people we can support, improved capacity of team, etc)
- Negative impact (eg decreased numbers of people we can support, decreased capacity of team, etc)
- Not applicable - no change in relevant funding
- We do not provide this service
- Did not answer

“The main impact of reduced or standstill of funding is the development and innovation of services, as well as the day to day running of the organisation. Other streams of funding are harder than ever to maintain, our costs have risen and without a guaranteed sustainable increasing income it is difficult to promise things to our families without knowing that money is accompanying our ideas. It also affects our ability to reward our staff, which in turn affects morale, recruitment and retention. The standstill has meant some of our current services have had to be adjusted slightly to ensure cost efficiencies and our more ambitious developments put on hold until we can raise the funds.”

Hazel South, Ellenor

“Where some CCGs have continued to support us financially, we have had the security to plan and therefore ultimately hopefully deliver a better quality of service to children and families. Where some CCG areas refuse to contribute towards the cost of care it puts pressure on the service and creates inequality within the service.”

Hazel Ryan, Richard House Children’s Hospice

“The same care is provided. There is still pressure put on the hospice to raise funds to cover the cost of care. As CCGs work differently, some CCGs are limiting the funds that were given previously and are asking for a needs assessment score to be used for children, to determine the amount of respite given.”

A children’s hospice

“We are in a stronger position due to good reserves and we are growing our non-legacy income. However, once legacy income falls away permanently, we will be unsustainable so are looking for different ways of providing services for the growth in demand and exploring partnerships and backroom operations.”

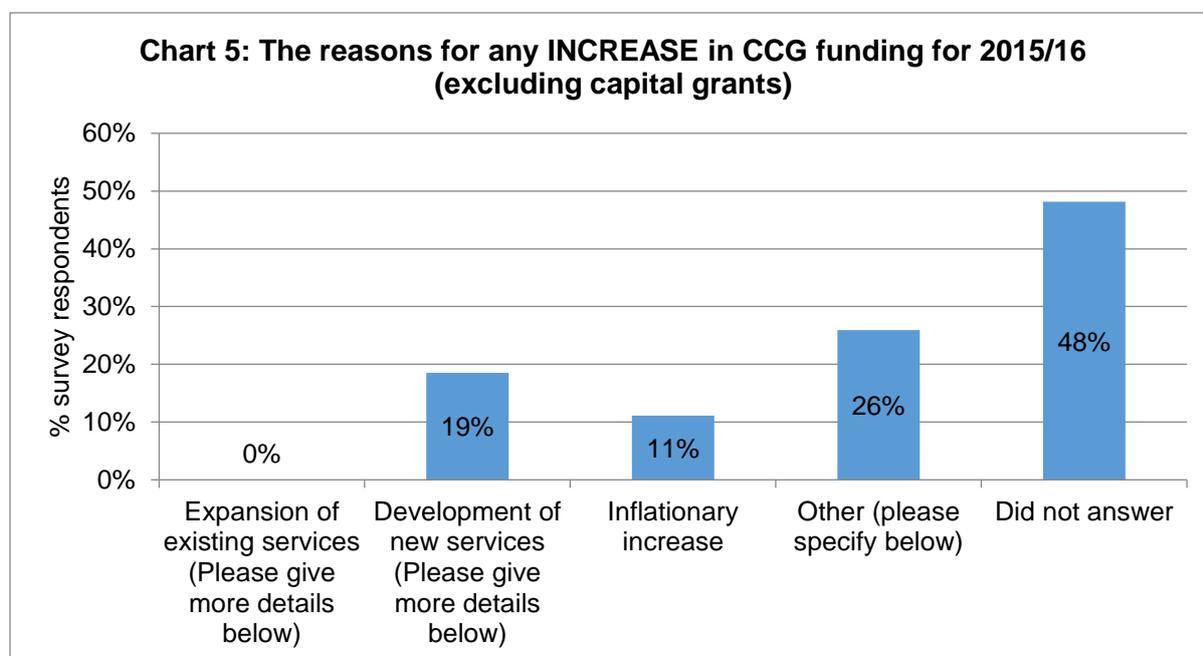
David Houston, Trinity Hospice and Brian House Children's Hospice

“Actual amounts of funding received from any commissioning source in a given year can be quite variable, dependent on the caseload and the availability of funds. This is especially so as our caseload is characterised by a relatively small number of patients from a large number of different CCGs. Sadly it is hard to engage with our "host" CCG, for whom we have the largest caseload, and the CCG declines to make any funding contribution towards children's & young adults' hospice care provided”

A children’s hospice

CCGs' have a range of reasons for increasing their funding to charities

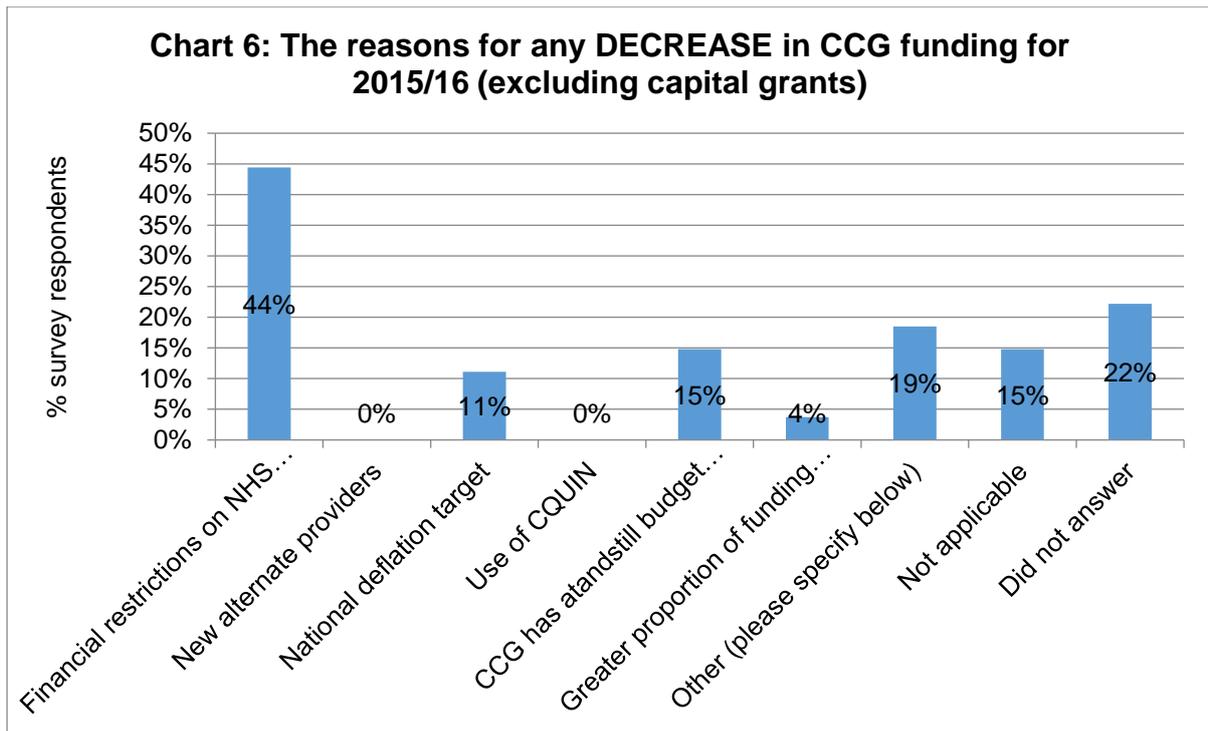
15. The third of charities (33%) which received an increase from their CCG have told us that there were a variety of reasons that CCGs gave for doing this. 19% of charities stated that their increase was attributed to a new service they had developed. 11% received more to reflect an increase in inflation. No providers reported being given more money by their CCGs to expand existing services.



Financial restrictions on CCGs are the most common reason given for funding being reduced: 44% of charities state that financial restrictions on their commissioners were a reason for their decrease in CCG funding

16. As Chart 6 shows, 44% of charities state that financial restrictions on their commissioners were a reason for their decrease in CCG funding. 15% reported that it was because their CCGs budgets had been frozen. 11% attributed the decrease to their CCGs applying the deflator recommended by NHS England to provider contracts⁴.

⁴ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/422554/2015-16_tariff_arrangements_Q_A_v9_-_published.pdf



CCGs' contribution to the cost of providing children's palliative care in the voluntary sector was more variable in 2015/16 compared to 2014/15

17. The standard deviation in CCGs' contributions to the cost of providing children's palliative care in the voluntary sector has risen from 7.71% in 2014/15 to 8.25% in 2015/16.

18. As shown in charts 7, 8 and 9, there was a wider variation in CCGs' contributions to the amounts of money charities need to provide children's palliative care in 2015/16 compared to 2014/15:

- The maximum contribution received by a charity in 2015/16 was 31%.
- One charity another received no funding at all.
- 41% of organisations received between 1% and 10%, while 19% received between 11% and 20%.

Chart 7: CCGs' contribution to the cost of providing children's palliative care in the voluntary sector

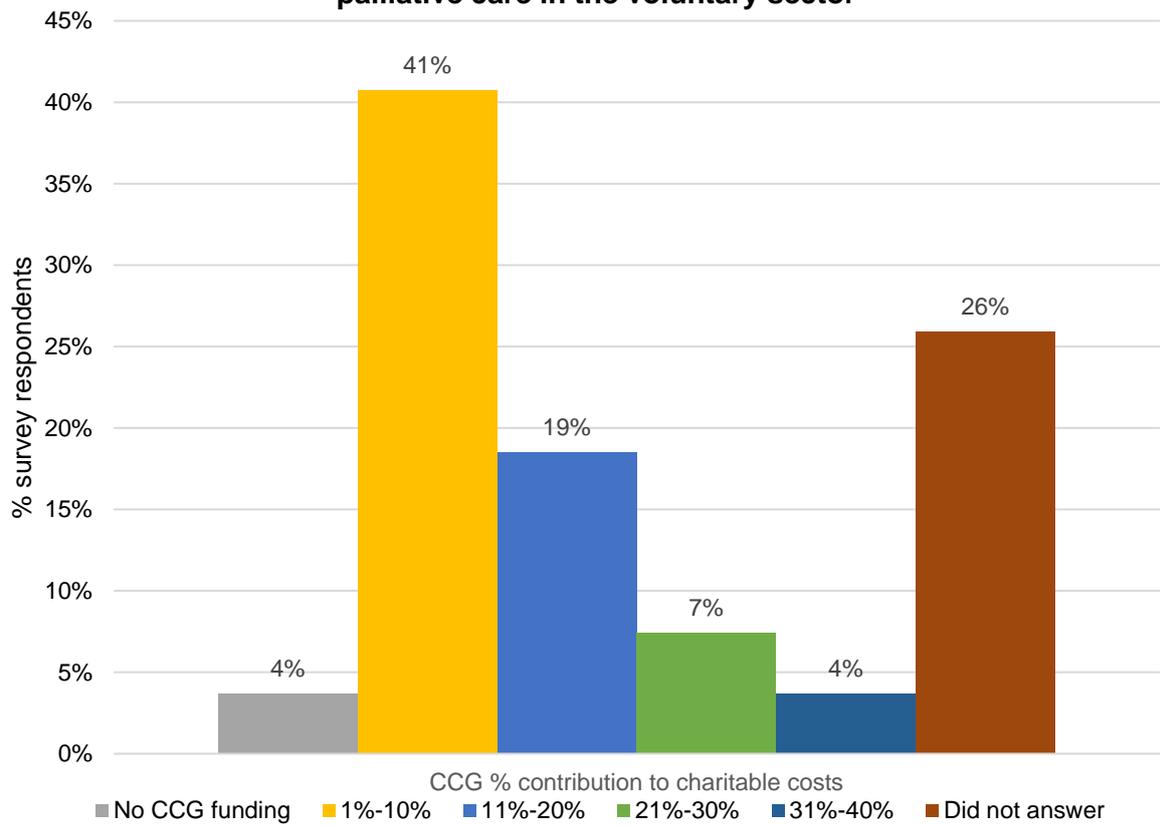
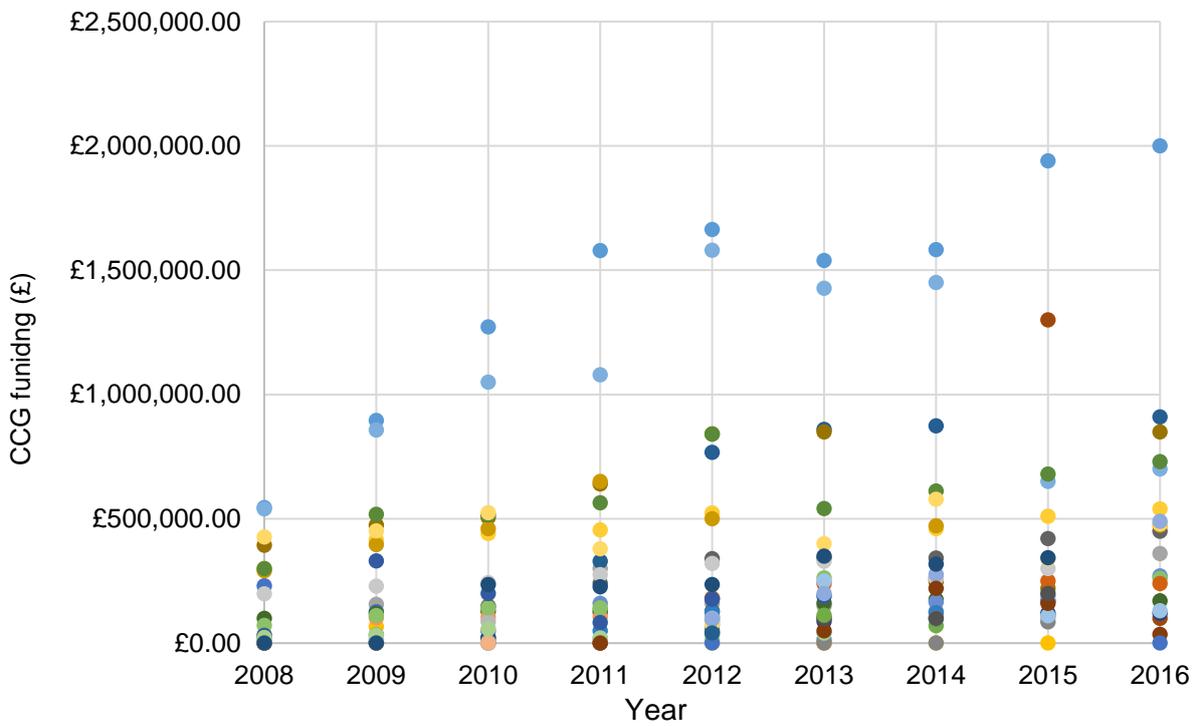
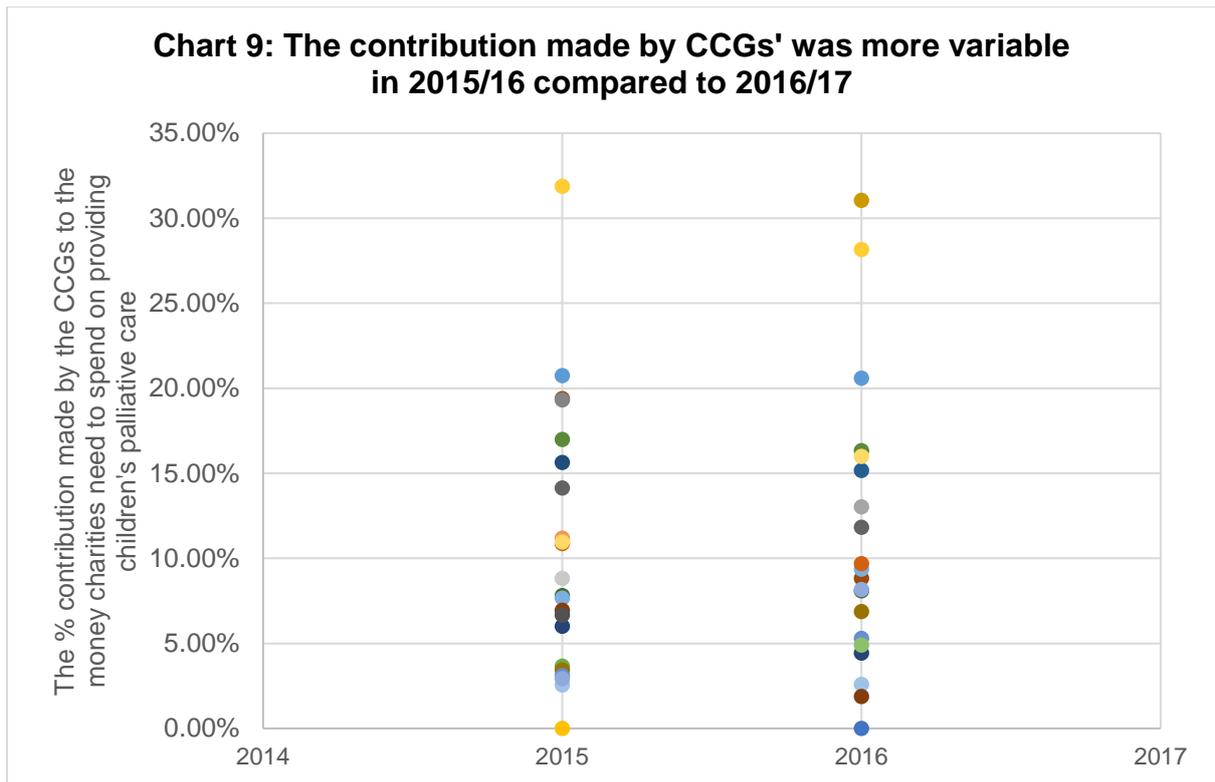


Chart 8: The variability of CCG funding 2007/08 - 2015/16





Local authorities' contribution to the costs incurred by charities has become less variable compared to 2014/15

19. The standard deviation in local authorities' contributions to the cost of providing children's palliative care in the voluntary sector has fallen from 4.25% in 2014/15 to 2.58% in 2015/16. The smaller range of contributions by local authorities is demonstrated in charts 10, 11 and 12.
20. As shown in Chart 10, there is a wide range in local authorities' contributions. The maximum contribution received by a charity in 2015/16 was 12%. 30% of charities received no funding at all. 15% of organisations received between 0% and 1%, while 19% received between 1% and 2%.

Chart 10: Local authorities' % contribution to the cost of providing children's palliative care in the voluntary sector

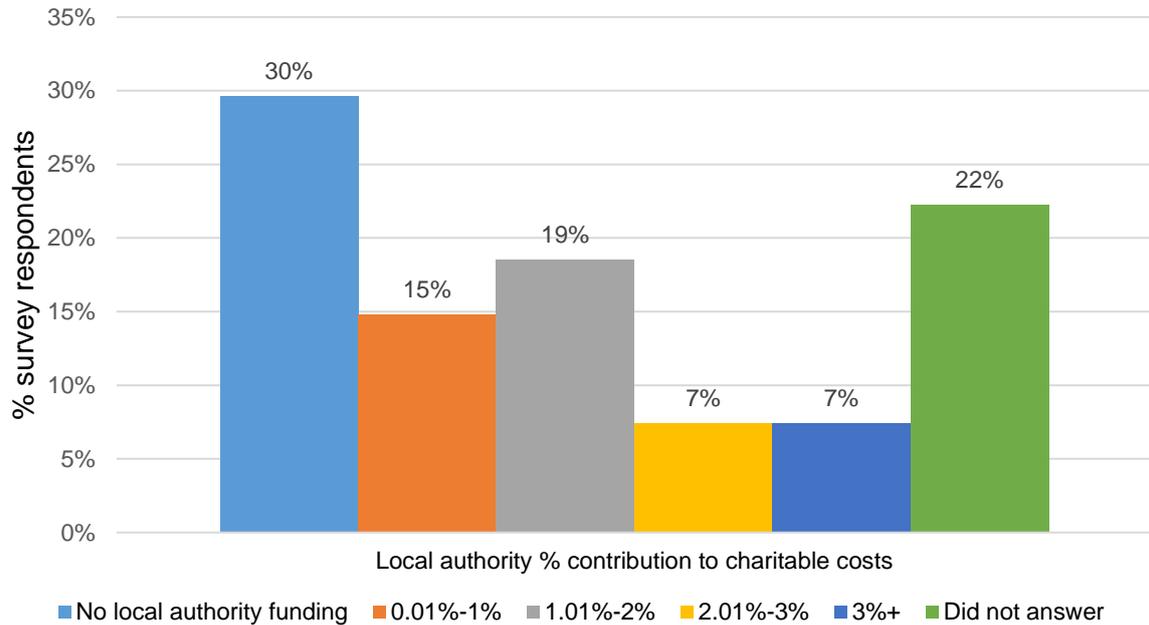


Chart 11: The variability of local authority funding 2007/08 - 2015/16

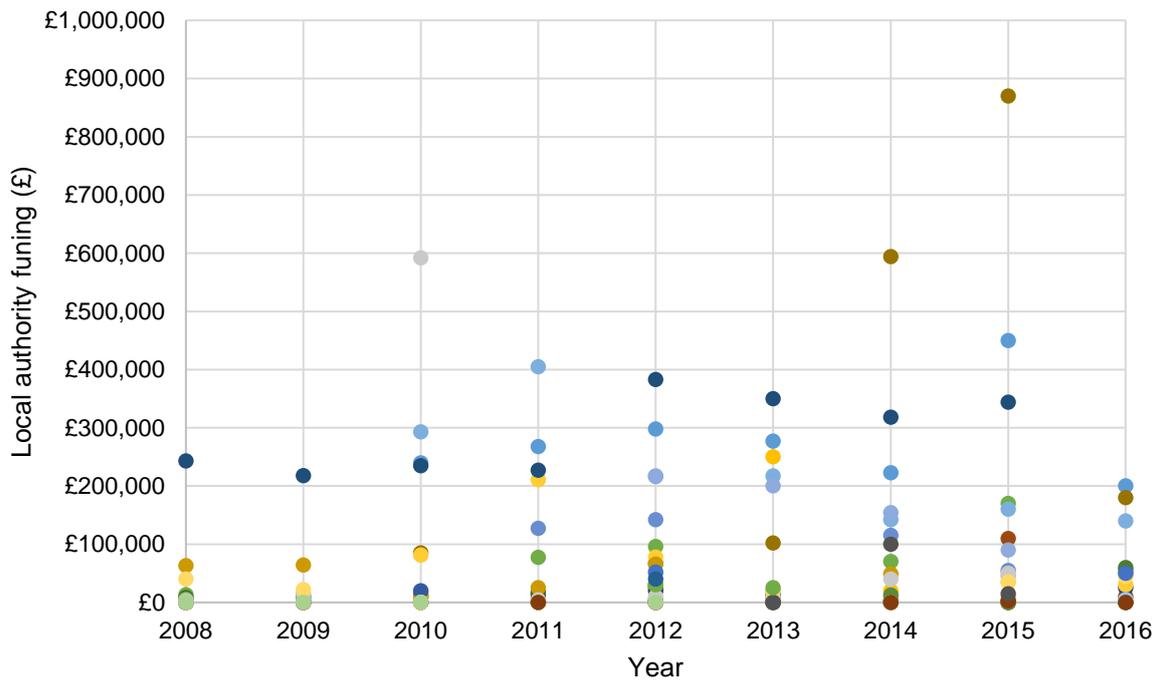
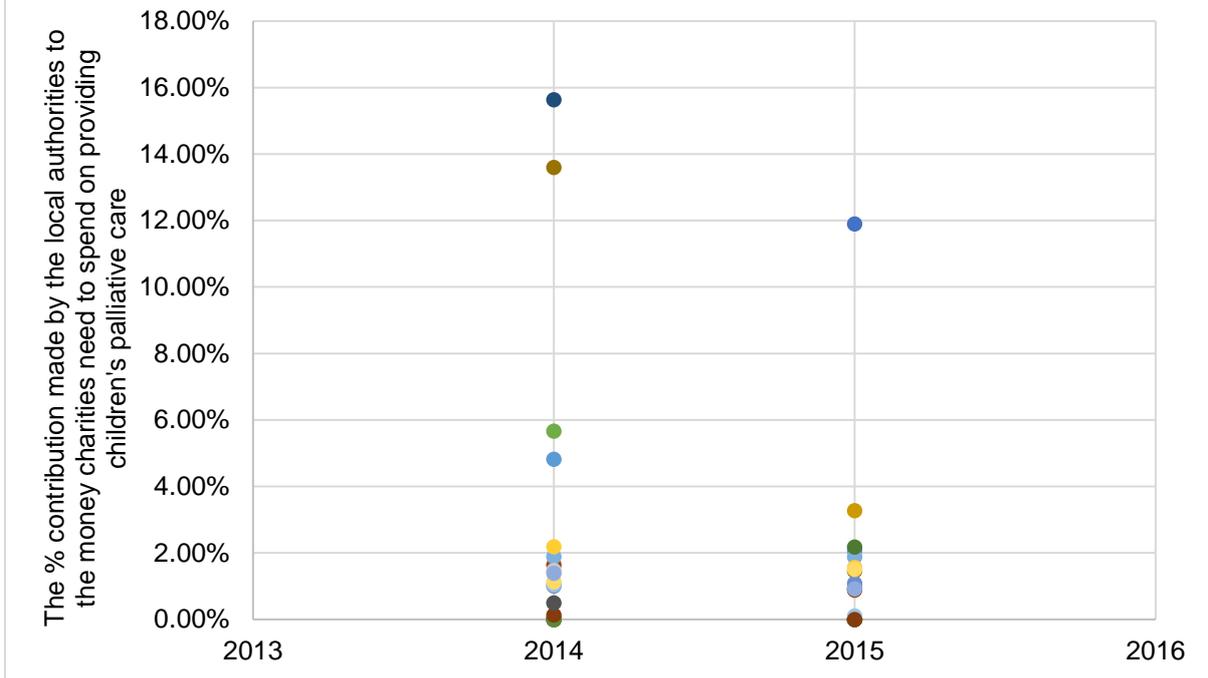


Chart 12: Local authority contributions to costs became less variable between 2014/15 and 2015/16



Overall, the state’s contribution to the cost of providing children’s palliative care in the voluntary sector is more variable in 2015/16 compared to 2014/15

21. When taking the NHS children’s hospice grant and funding from CCGs and local authorities into account, the standard deviation in the state’s contribution to the cost of providing children’s palliative care in the voluntary sector has risen to 12% in 2015/16 from 10% in 2014/15.
22. As shown in charts 13 and 14, there was a wider range in the state’s contributions in 2015/16 compared to 2014/15. The maximum contribution received by a charity in 2015/16 was over half (53%). The lowest was 2%. 30% of charities received a contribution of between 21% and 30%. 30% of organisations received between 11% and 20%.

Chart 13: State's overall % contribution to the cost of providing children's palliative care in the voluntary sector

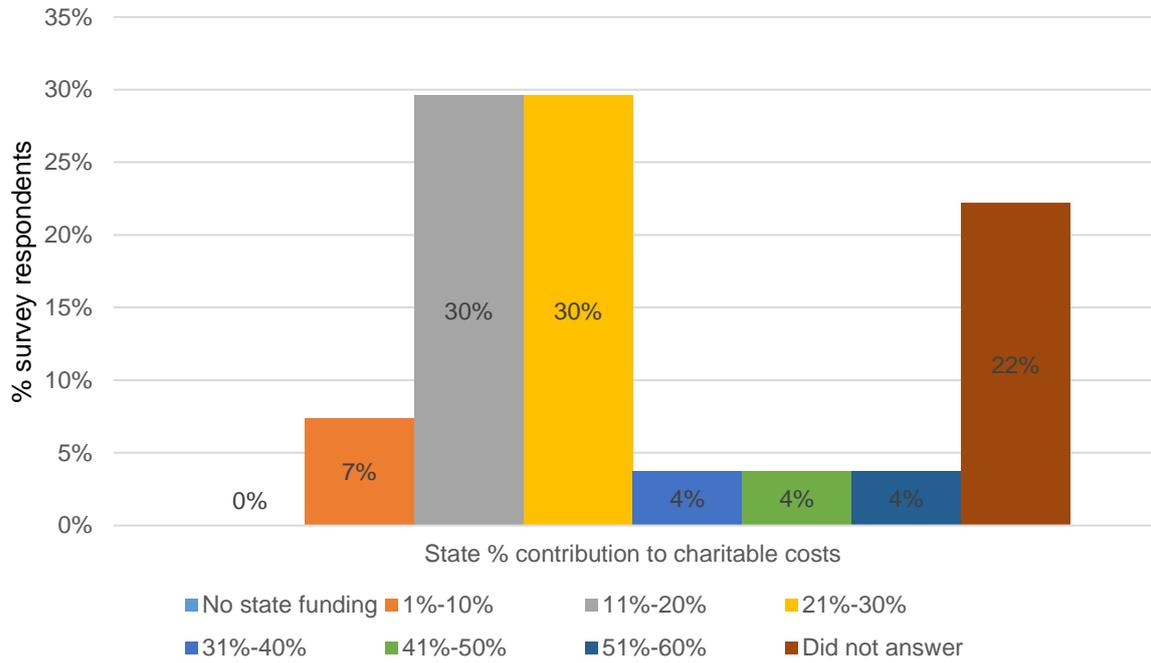
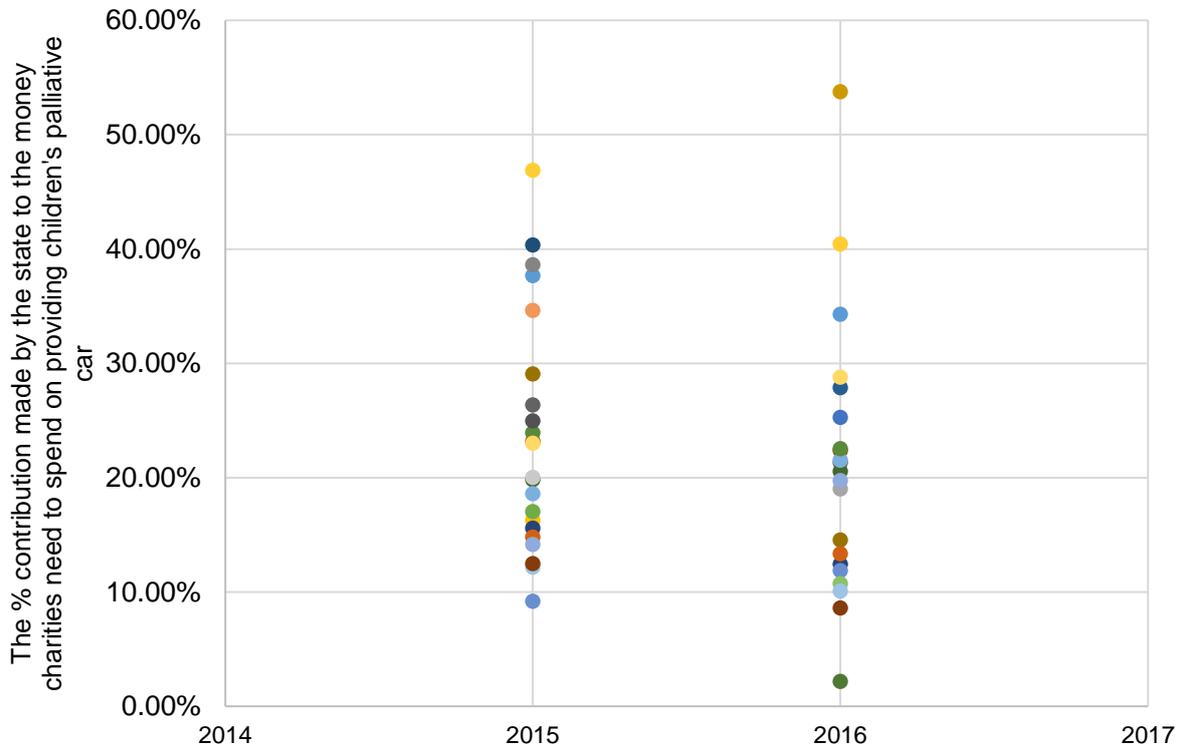
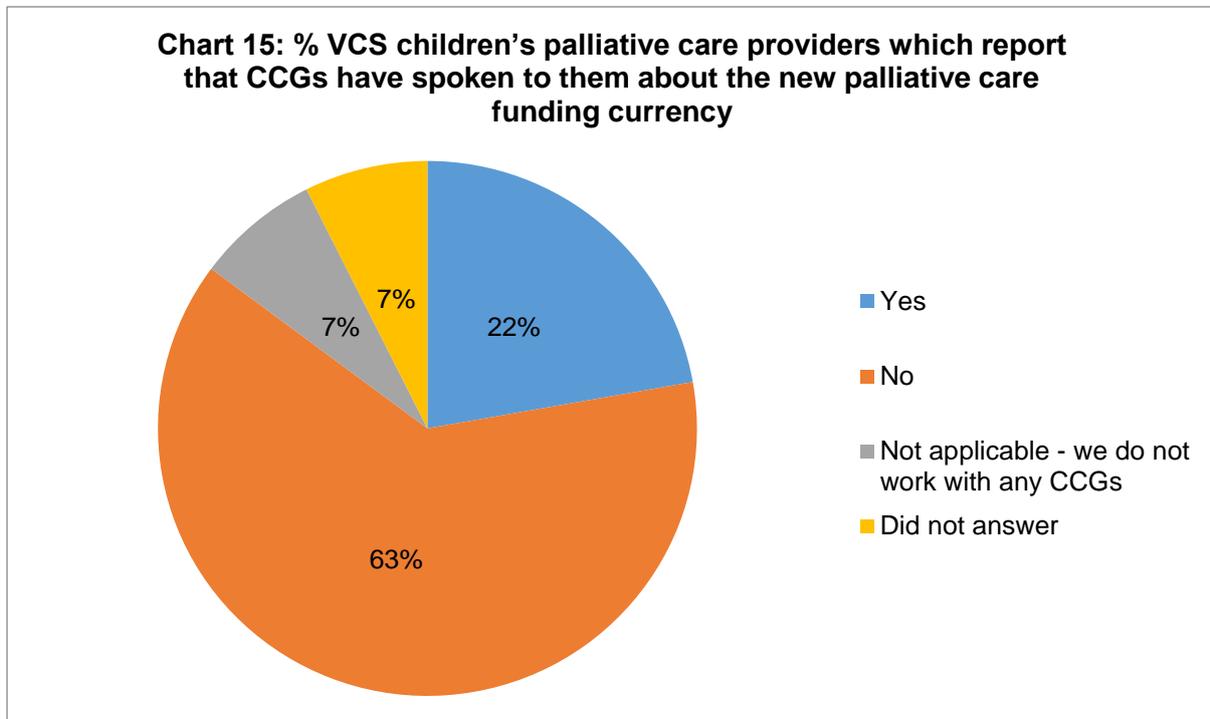


Chart 14: Overall statutory funding was more variable in 2015/16 compared to 2014/15



A minority of charities report that CCGs have spoken to them about the new palliative care funding currency

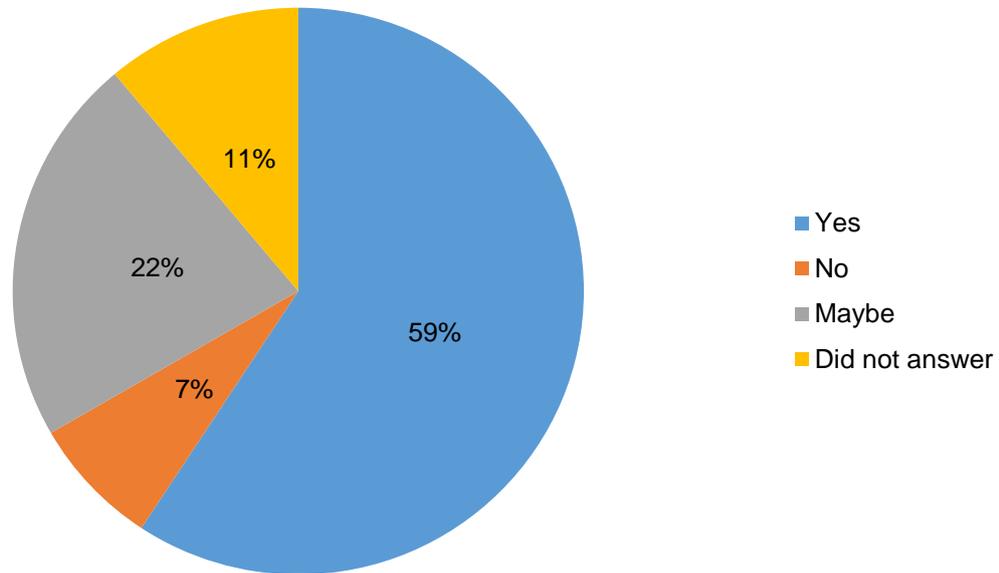
23. CCGs will be able to use a new series of per-patient currencies to fund children’s palliative care from April 2017. Despite this (and as Chart 15 shows) a small minority (22%) of charities have been approached by their CCGs to discuss it. Nearly two thirds (63%) have not been spoken to by their CCG about the currency.



Over half of charities would be forced to reduce their services if the children’s hospice grant was no longer available

24. 24 charities told us what the impact would be on their services if the NHS England children’s hospice grant was no longer available to them in 2016/17. As shown in Chart 16, a similar majority (59%) to our 2015 survey (58%) stated that it would have a negative impact on services. 7% said that it would not, 22% said maybe and 11% did not answer.

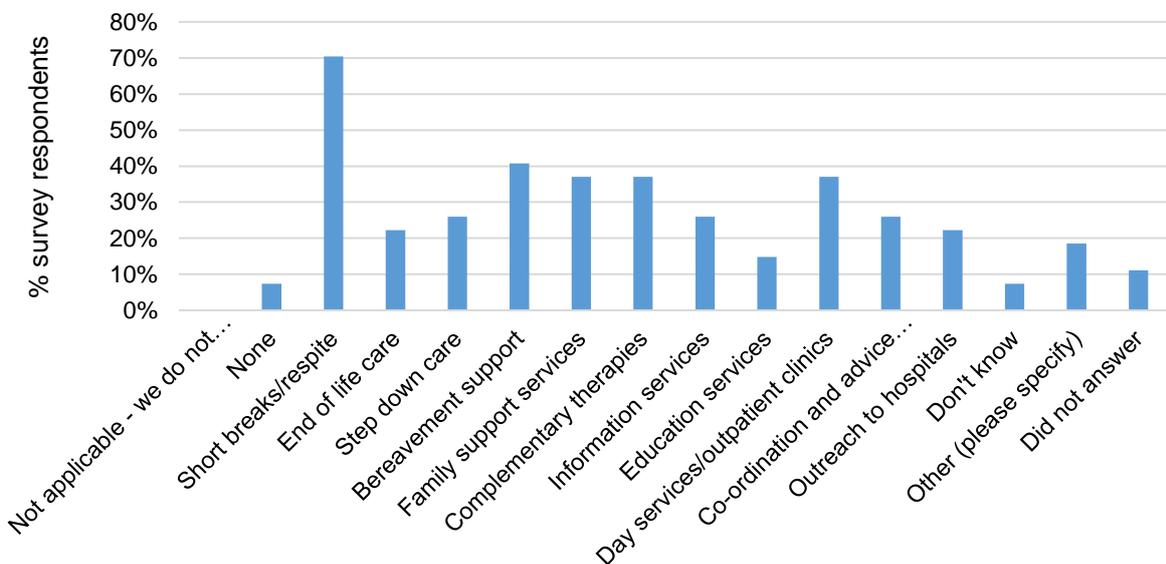
Chart 16: % VCS children's palliative care providers which envisage that they would reduce their services in the event that the grant funding was no longer available in 2016/17



Short breaks and bereavement support are the most likely services to be cut if the children's hospice grant were to be removed

25. 24 charities told us which services would be reduced if the NHS England children's hospice grant was no longer available to them in 2016/17. As Chart 17 shows, over two thirds (70%) said that they would be most likely to cut short breaks, followed by bereavement support (41%), family support services, complementary therapies and day services/outpatient clinics (all 37%). The proportion stating that short breaks would be the most likely service to be cut has risen from 58% in 2015.

Chart 17: % VCS organisations which would reduce services if the children's hospice grant was no longer available in 2016/17



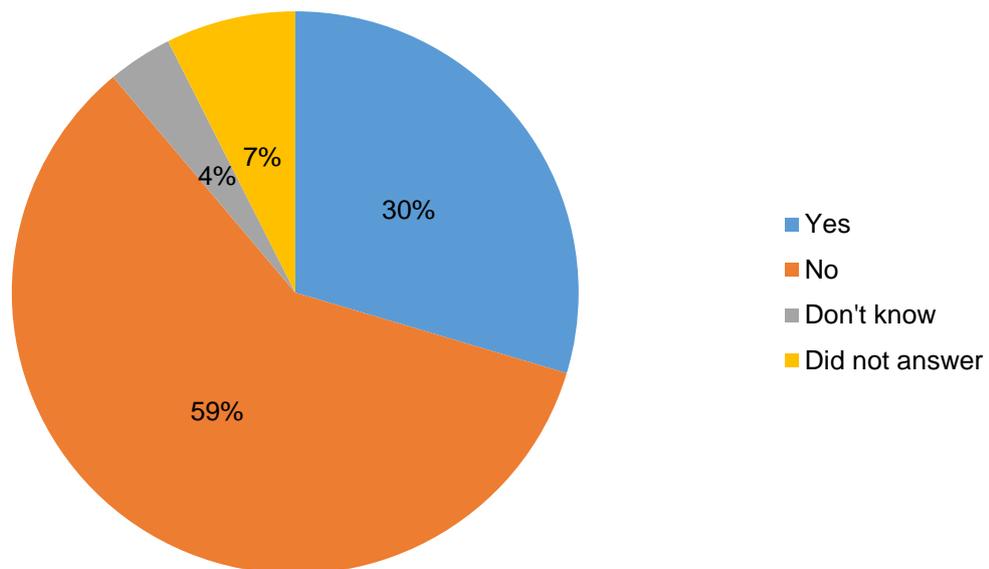
“If we no longer had the hospice grant, this would have a large impact on the funding we would have and therefore the services we could provide. End of Life Care would still be our priority and we would aim not to reduce this part of the service. However, other services would probably need to be reduced in accordance with the funding.”

A children’s hospice

A minority of charities received personal budgets funding in 2015/16

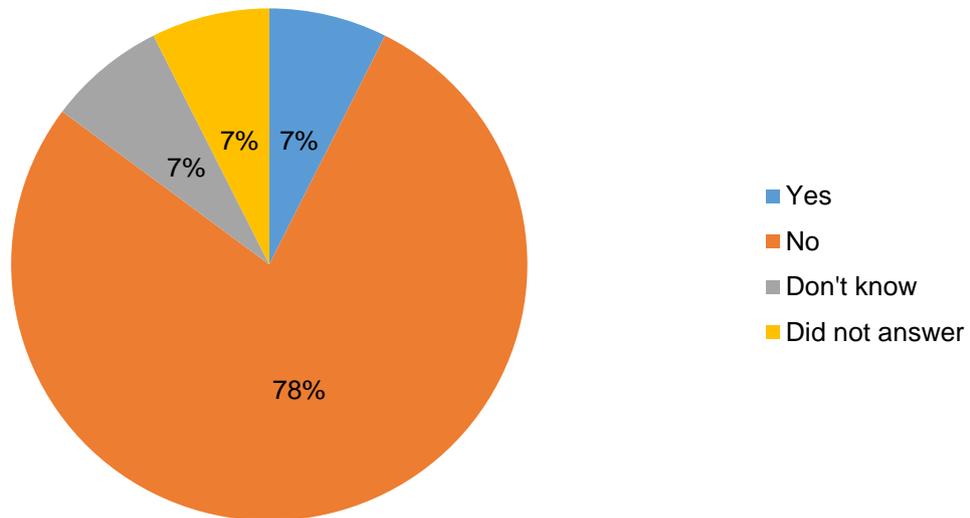
26. NHS England intends 50-100,000 people to have a personal health budget or integrated personal budget in 2020. NHS England estimates that 4,000 people currently have one. As Chart 18 shows, just under a third (30%) of charities received personal budgets funding in 2015/16, a small increase on the 27% which reported personal budget funding in 2014/15. The proportion of those which said that they had not received personal budget funding fell slightly from 62% in 2014/15 to 59% in 2015/16.

Chart 18: % VCS organisations which received funding from personal budgets during 2015/16



27. Children and young people aged 0-25 with an education, health and care (EHC) plan resulting from a special educational need (SEN) have had a right to a personal budget since April 2015. As Chart 19 shows, 78% of charities have not received funding from EHC-related personal budgets in 2015/16. Only 7% have.

Chart 19: % VCS organisations which received funding from education, health and care (EHC) personal budgets for children and young people 0-25 years with a special educational need in 2015/16?

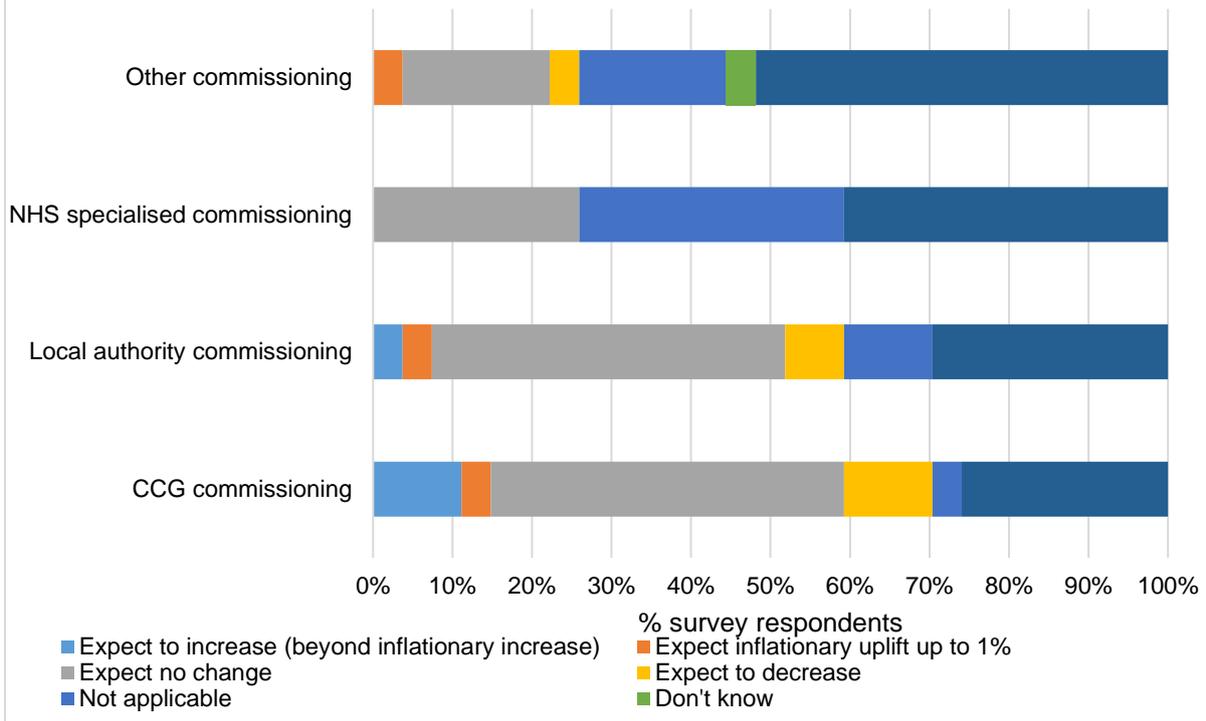


Funding in 2016/17

Charities are slightly more pessimistic about their CCG funding for 2016/17

28. As Chart 20 shows, 'No change' was still the most popular answer from charities (44%) when they were asked how they expected their CCG funding to change in 2016/17. This was slightly reduced from the proportion which expected no change in our 2015 survey (54%). 15% reported that they expected some sort of increase (down from 23% in 2015). The proportion expecting a decrease rose slightly from 8% in 2015 to 11% in 2016.
29. No change (44%) was also the most prevalent answer from charities in response to our question about how they expected their local authority funding to change. This was down from 50% who said this in 2015. While 12% expected their local authority funding to decrease when asked in 2015, 7% expected a decrease when asked in 2016.

Chart 20: How VCS organisations expect their levels of funding from statutory sources to change in 2016/17, compared to 2015/16



“Unless we invest significant time and resources in building relationships, we expect relationships with local authority commissioners to decrease as funding lessens. Relationships with HWBs will stay as they are as they are limited in awareness of Rainbow Trust and our work.”

Emma Buttle-Smith, Rainbow Trust Children’s Charity

30. Charities continue to struggle to access funding from NHS England to provide specialised children’s palliative care:

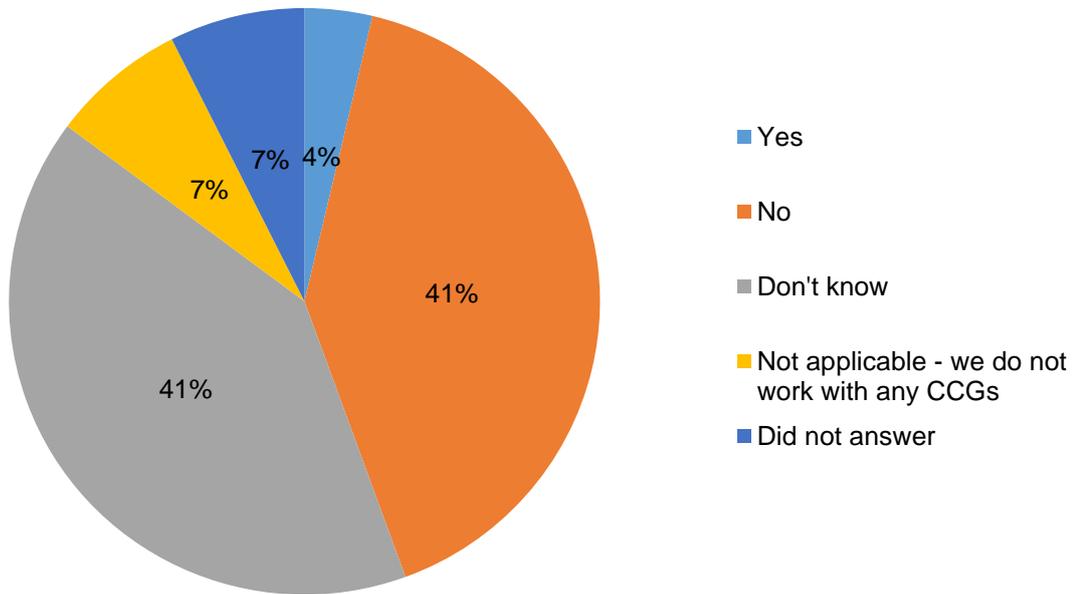
“Despite providing paediatric palliative medicine at a specialised level, there is no evident means to access associated funds through NHS England commissioning.”

A children’s hospice

Fewer charities expect their CCGs to use the new children’s palliative care funding currency compared to what we found in 2015

31. As Chart 21 shows, an even smaller proportion (4%) of charities expect their CCGs to use the new palliative care funding currency compared to 2015 (8%). A much greater proportion (41%) stated that they did not expect their CCGs to use the currency compared to the 23% in 2015.

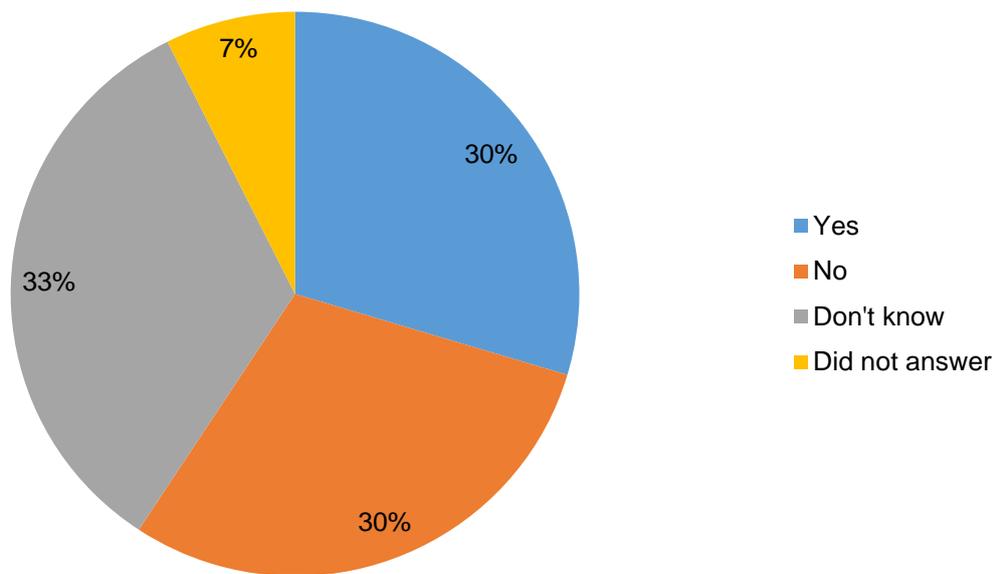
Chart 21: % of VCS organisations which report that a CCG they work with plan to use the palliative care development currency



A similar proportion of charities expected to receive funding from personal in 2016/17 compared to expectations in 2015/16

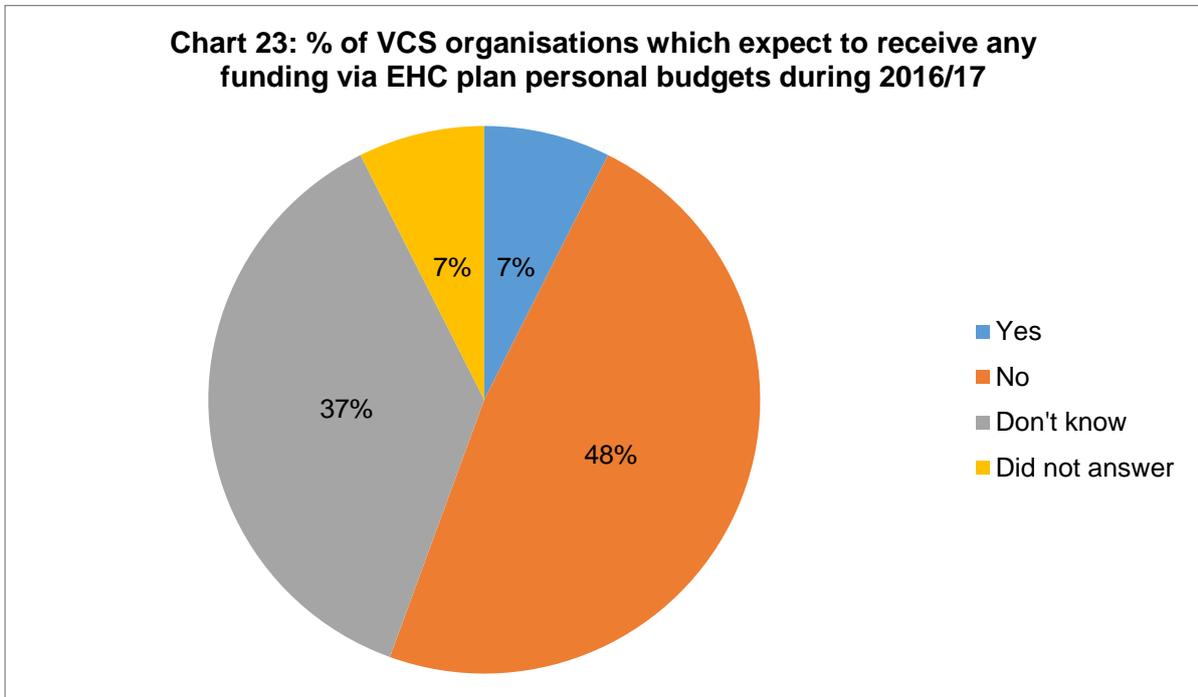
32. As Chart 22 shows, 30% of charities expect to receive funding via personal budgets in 2016/17, an almost identical proportion to the 31% who reported this 2015. 30% expect not to receive any personal budgets funding 2016/17, a slight increase on the 27% reported in 2015.

Chart 22: % of VCS organisations which expect to receive any funding via personal budgets during 2016/17



Almost half of charities expect no funding from education, health and care (EHC) plan personal budgets in 2016/17

33. As Chart 23 shows, 48% of charities expect to receive no funding from EHC personal budgets in 2016/16. 7% do expect this type of funding, while over a third (37%) are unsure.



Relationships, contracts and agreements in 2015/16

Charities have to manage relationships with many different statutory organisations; CCGs and local authorities should prioritise working jointly at a sub-regional level and provide charities with single points of contact

34. Of the 20 charities which told us how many CCGs they were commissioned by in 2015/16, the mean response was eight. This remains unchanged from 2014/15. One respondent told us that they were commissioned by 23 different CCGs.
35. Charities had an average of six funding agreements with CCGs in 2015/16. This has risen from four in 2014/15. One respondent told us that they had funding agreements with 24 different CCGs.
36. Of the 18 charities which told us how many local authorities they were commissioned by in 2015/16, the mean response was two. This has fallen from three in 2014/15.
37. Charities had an average of two funding agreements with local authorities in 2015/16. This has fallen from three in 2014/15.

Some charities report that their CCGs still do not have relationships with them

38. As Chart 24 shows, despite the variable funding they provide, the vast majority of CCGs do have relationships with their local charities, with 89% of the latter reporting that they are engaged with their CCGs. However, 4% of charities still report that their CCGs are not engaged with them, which is the same proportion that reported this in 2015.

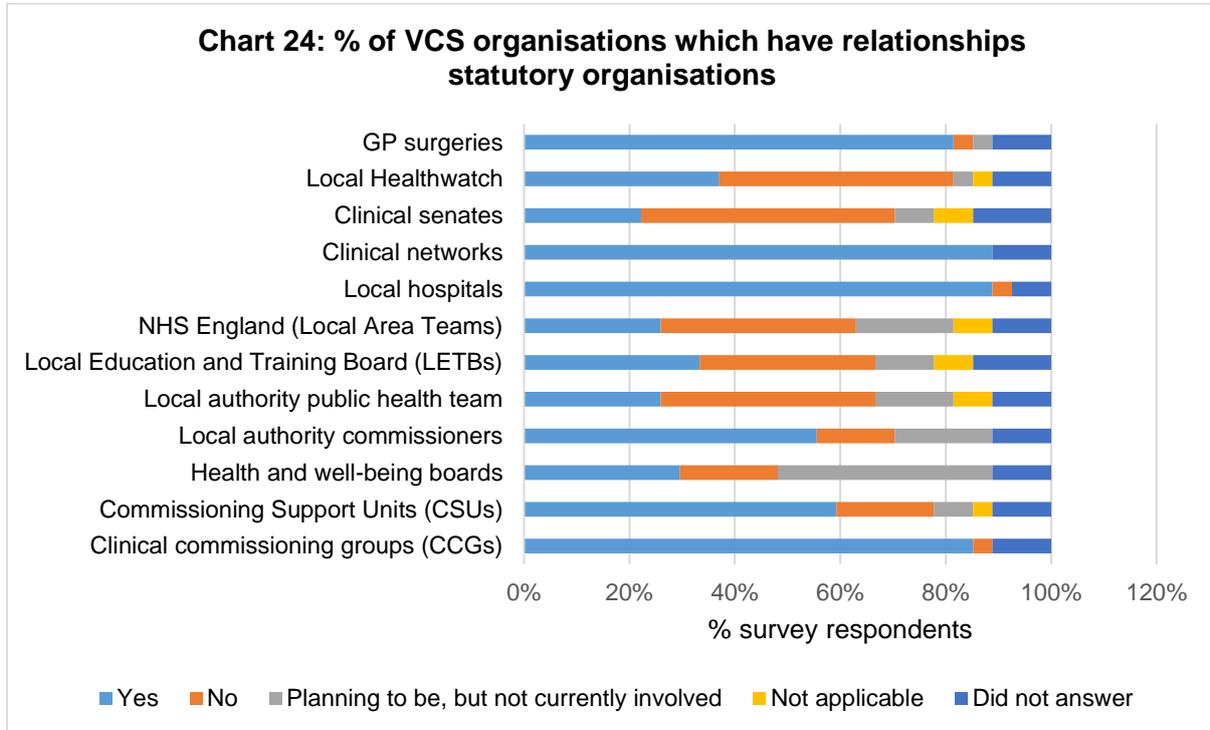
A smaller proportion of charities report that they have relationships with their local authorities and health and wellbeing boards compared to CCGs

39. 15% of charities report that their local authority commissioners do not have a relationship with them (also see Chart 24). This has risen from the 8% which reported in this in 2015. This reflects the fact that only 18% of local authorities commission their local children's hospice, which Together for Short Lives learned about as a result of a series of freedom of information (FOI) requests in April 2016⁵. The same survey found that seven CCGs (4%) and two local authorities (2%) do not commission children's hospices because they are charities. This is despite the Department of Health, NHS England and Public Health England recognising the voluntary, community and social enterprise (VCSE) sector is an important partner for statutory health and social care agencies in playing a key role in improving health, well-being and care outcomes⁶.
40. Nearly one in five (19%) VCS children's palliative care providers state that their local health and wellbeing boards do not have a relationship with them. This is particularly disappointing given the latter's vital role in producing local joint strategic needs assessments (JSNAs). These assess the health and wellbeing needs of their

⁵ Together for Short Lives. 2016. Commissioning children's palliative care in England: the results of Together for Short Lives' freedom of information requests of NHS clinical commissioning groups (CCGs) and local authorities in England. Available to download from: www.togetherforshortlives.org.uk/datamap

⁶ Department for Health, NHS England, Public Health England. 2016. Review of partnerships and investment in the voluntary sector. Available to download at: <http://bit.ly/1XBY5jx>

local populations and should inform what CCGs and local authorities decide to commission. For children and young people both the special educational needs and disability (SEND) code of practice⁷ and guidance from the Department for Health⁸ currently state that children who need palliative care should be included in JSNAs.



“Uncertainty over NHS and local authority resourcing. Continual organisational restructuring and loss of organisational memory/relationships. Slow movement and even some reversal of move towards NHS and social care integration.”

A children’s hospice

“Relationships are hugely variable between individual commissioners, however in 2015-16 we secured new funding from an additional 3 CCGs (2 of whom were part of a joint agreement). This is fruition of work over a number of years.

“Commissioners who want to engage, do so; those that don't, don't! It is hard to establish any relationship with the Health and Wellbeing Board.

A children’s hospice

⁷ Department for Education. 2014. Special educational needs and disability code of practice: 0 to 25 years. Available to download at: <https://www.gov.uk/government/publications/send-code-of-practice-0-to-25>

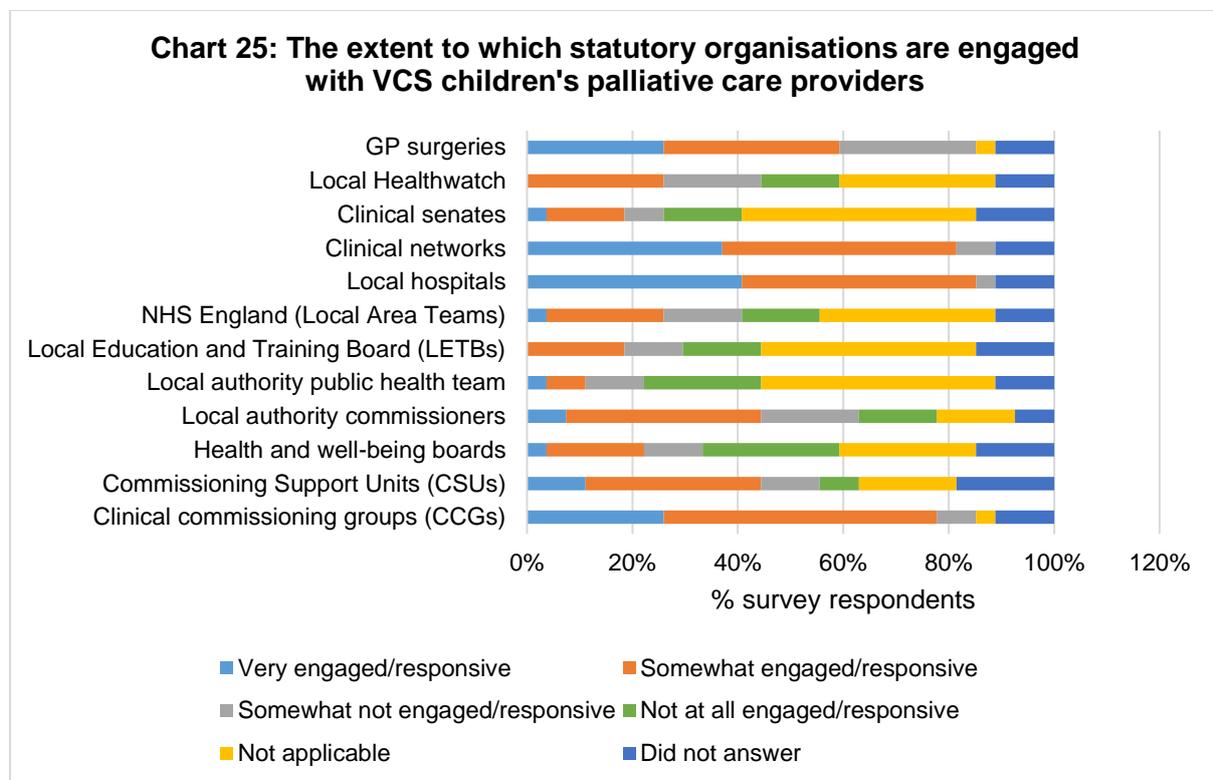
⁸ Department for Health. 2014. Children with special educational and complex needs: guidance for Health and Wellbeing Boards. Available to download at: <http://bit.ly/1xBM5zq>

Most charities report that their CCGs are engaged and respond to them

41. As with Chart 24, we welcome the fact that 78% of charities state that their CCGs are either very or somewhat engaged with them (see Chart 25). We are concerned, however, that 7% of charities state that their CCGs are somewhat not engaged or responsive.

However, a third of charities tell us that their local authorities and health and wellbeing boards are not engaged

42. Disappointingly, Chart 25 also demonstrates that 34% of charities report that their local authorities are either not at all or somewhat not engaged with them. 37% report that that their local health and wellbeing boards are either not at all or somewhat not engaged with them.



A majority of charities state that their relationships with CCG, local authorities and health and wellbeing boards were either worse or the same in 2015/16 compared to 2014/15

43. Chart 26 demonstrates how 59% of charities told us that their relationships with their local CCGs remained the same (48%) or got worse (11%) between 2014/15 and 2015/16. This is a marginal improvement on the 66% who reported no change or a worsening between 2013/14 and 2014/15. 33% said they had got better between

“Our local CCGs are keen to work with us as we provide additionality for their funding, and we are generating savings in overall costs to them by reducing unnecessary hospital admissions and bed nights.”

Jackie Bliss, Havens Hospices

2014/15 and 2015/16, similar to the 31% which reported this between 2014/15 and 2015/16.

“We have had to negotiate our main 3 year contract with the 6 local CCGs, which has built our relationships with them. Subsequently our clinical team has been invited to complex care MDT panels in some of the CCG areas and this will have a positive impact on the quality of care for these children and young people as they will benefit from a more joined-up and coordinated approach between all agencies.”

Hazel Ryan, Richard House

44. 67% of charities told us that their relationships with their local authority commissioners remained the same (63%) or got worse (4%) between 2014/15 and 2015/16. This is a marginal improvement on the 70% who reported no change or a worsening between 2013/14 and 2014/15. 11% said they had got better between 2014/15 and 2015/16, which is a slight fall on the 15% which reported this between 2013/14 and 2014/15.

“Children with life shortening conditions are not a priority for LA services or the Health and Wellbeing Boards.”

Andy Goldsmith, Hope House

“Our director of care sits on a local children's health and well being board and our chief executive sits on a local well being board. This supports the organisation to develop and maintain relationships with the boards and their members.”

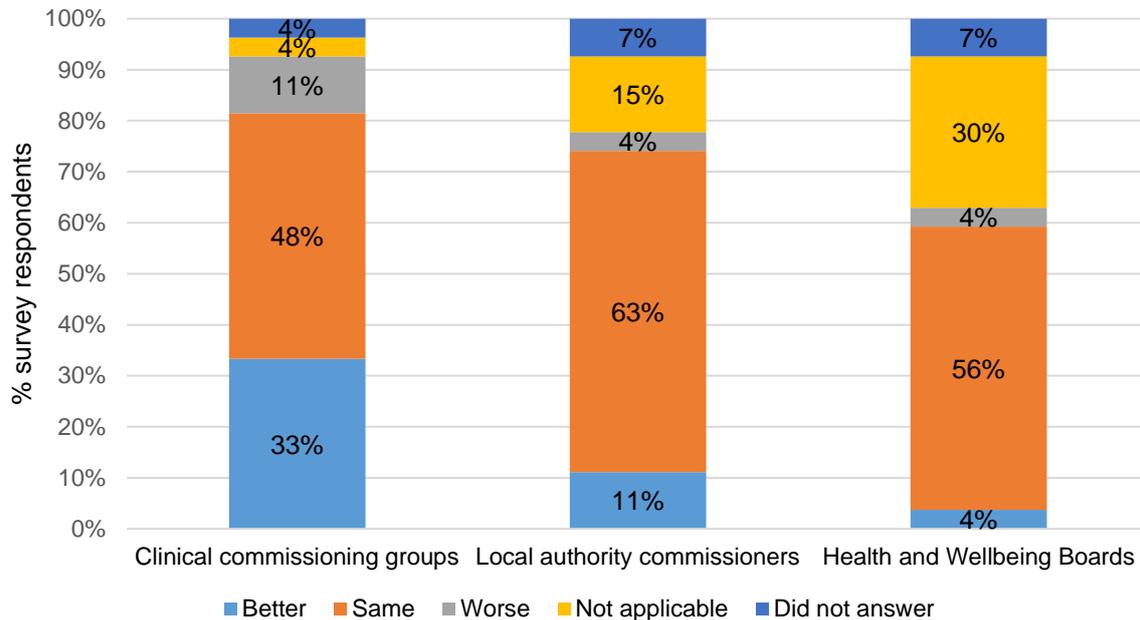
A children's hospice

“The biggest challenges are: the number of relationships; change and staff turnover at CCGs and local authorities; volume of admin involved, particularly with NHS commissioning; financial pressures on commissioners; lack of long-term agreements/contracts; majority of commissioners reviewing commissioning arrangements in order to manage demand and funding; involvement of CSUs and their requests for additional information and data as part of the quarterly reporting process; this seems disproportionate when compared to the bigger trusts which are fully funded.”

A children's hospice

45. 60% of charities told us that their relationships with their local health and wellbeing boards remained the same (56%) or got worse (4%) between 2014/15 and 2015/16. This is much greater than the 39% who reported no change or a worsening between 2013/14 and 2014/15. 4% said they had got better between 2014/15 and 2015/16, which is the same as recorded between 2013/14 and 2014/15.

Chart 26: How VCS organisations categorised their relationship with commissioners and key local health bodies during 2015/16 overall compared with 2014/15



Two thirds of charities are not engaged in their local sustainability and transformation plans (STPs)

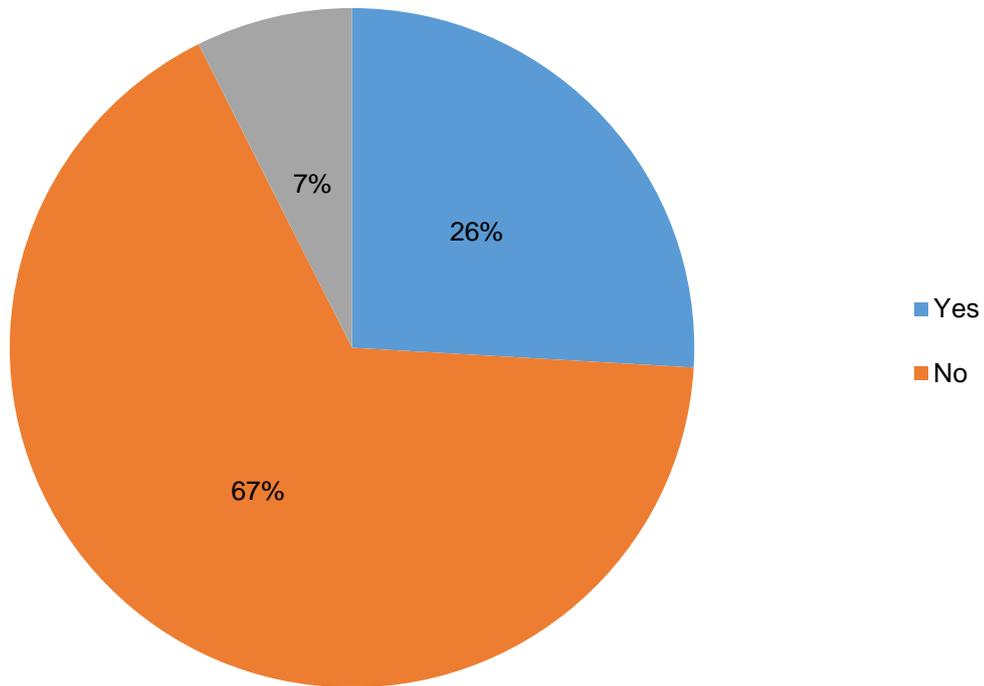
46. In December 2015, the NHS shared planning guidance 16/17 – 20/21⁹ outlined a new approach which aims to make sure that health and care services are built around the needs of local populations. To do this, every health and care system in England has been asked to produce a multi-year sustainability and transformation plan (STP). NHS England expects these to show how local services will evolve and become sustainable.

47. Given that the Independent Palliative Care Review recommended that children’s palliative care should be commissioned at a sub-regional level over a population level of one million¹⁰, Together for Short Lives regards STPs as an opportunity for CCGs and local authorities to work together to create the economies of scale necessary. It is therefore disappointing that two-thirds (67%) of charities report that they are not engaged in their STPs (see Chart 27).

⁹ <https://www.england.nhs.uk/ourwork/futurenhs/deliver-forward-view/>

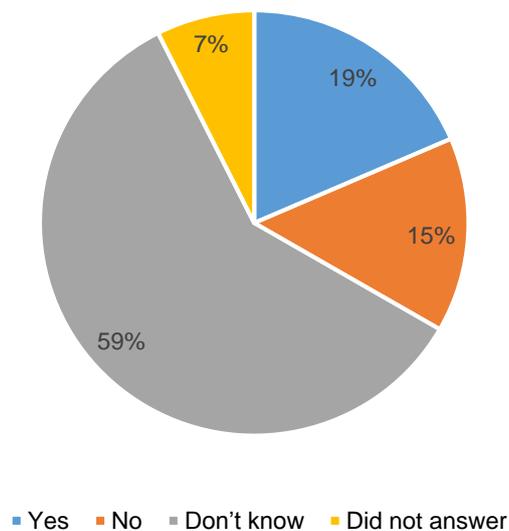
¹⁰ Hughes-Hallett T, Craft A, Davies C. 2011. Palliative Care Funding Review: Funding the Right Care and Support for Everyone - Creating a Fair and Transparent Funding System; the Final Report of the Palliative Care Funding Review – An Independent Review for the Secretary of State for Health. Available to download at: <http://bit.ly/15mBe4u>

Chart 27: % of VCS organisations engaged with the Sustainability and Transformation Plans in their footprint area



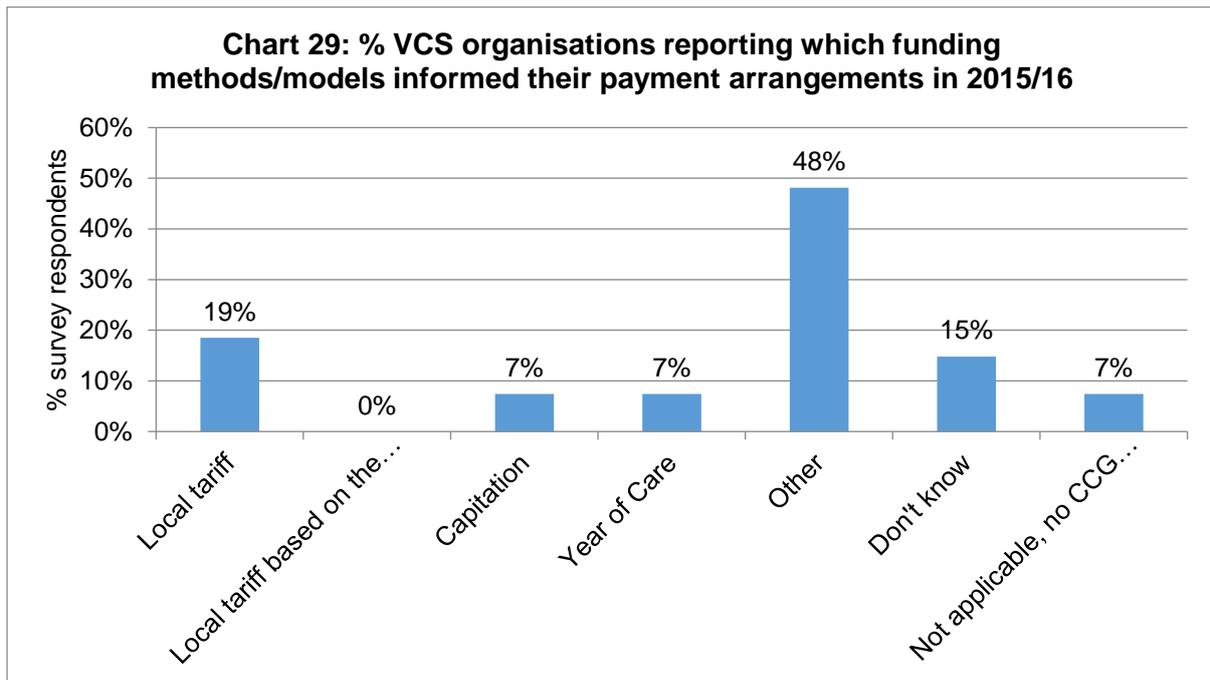
48. While we welcome the fact that nearly a fifth (19%) of charities state that palliative or end of life needs are reflected in their local STPs, we are concerned that 74% answered 'no' or 'don't know'.

Chart 28: % of VCS organisations reporting that the sustainability and transformation plans in your footprint area address palliative and/or end of life needs



There is little evidence that the new payment models set out in the NHS Five Year Forward View are being applied to charities yet

49. Despite the Five Year Forward View introducing new funding models including year of care and capitation to be used alongside per-patient tariffs and currencies, Chart 29 shows that there is little evidence that they were used widely in funding charities in 2015/16. 19% of our respondents state that local tariffs informed their payment arrangements in 2015/16, with even fewer reporting that capitation (7%) or year of care (7%) had done so. No organisations reported that arrangement were based on the palliative care development currency.



“We use a per bednight figure which is based on what the market will pay comparing with local acute and third sector provision.”

A children’s hospice

“We calculate our charges based on our costs, using the definition from the Palliative Care Funding Review guidance. We have a three tier system of charges, based on the level of acuity of the child and therefore the staffing requirements.”

Estelle Hudson, Demelza Hospice Care for Children

The most common form of funding agreement is block budget or bundled payment

50. As Chart 30 shows, our survey respondents had a mean of four block budget or bundled payment agreements with their CCGs in 2015/16. However, each respondent only had a mean of one block agreement which ran for more than 12 months.

51. Statutory funding seems to have become more sustainable in 2015/16. 91% of VCS providers’ NHS standard short form contract agreements run for more than 12

months. 87% of respondents' NHS standard contracts run for more than 12 months. In 2014/15, only 26% of all NHS standard contracts ran for more than 12 months.

52. However, for some, funding arrangements remain precarious:

“Aside from the NHS England Children's Hospice Grant, the majority of remainder of our statutory funding is based on one continuing care contract with child specific packages, and individual placement agreements for children as and when they require care. This makes it difficult to predict future funding and means our statutory income fluctuates according to the specific needs of a relatively small number of children.”

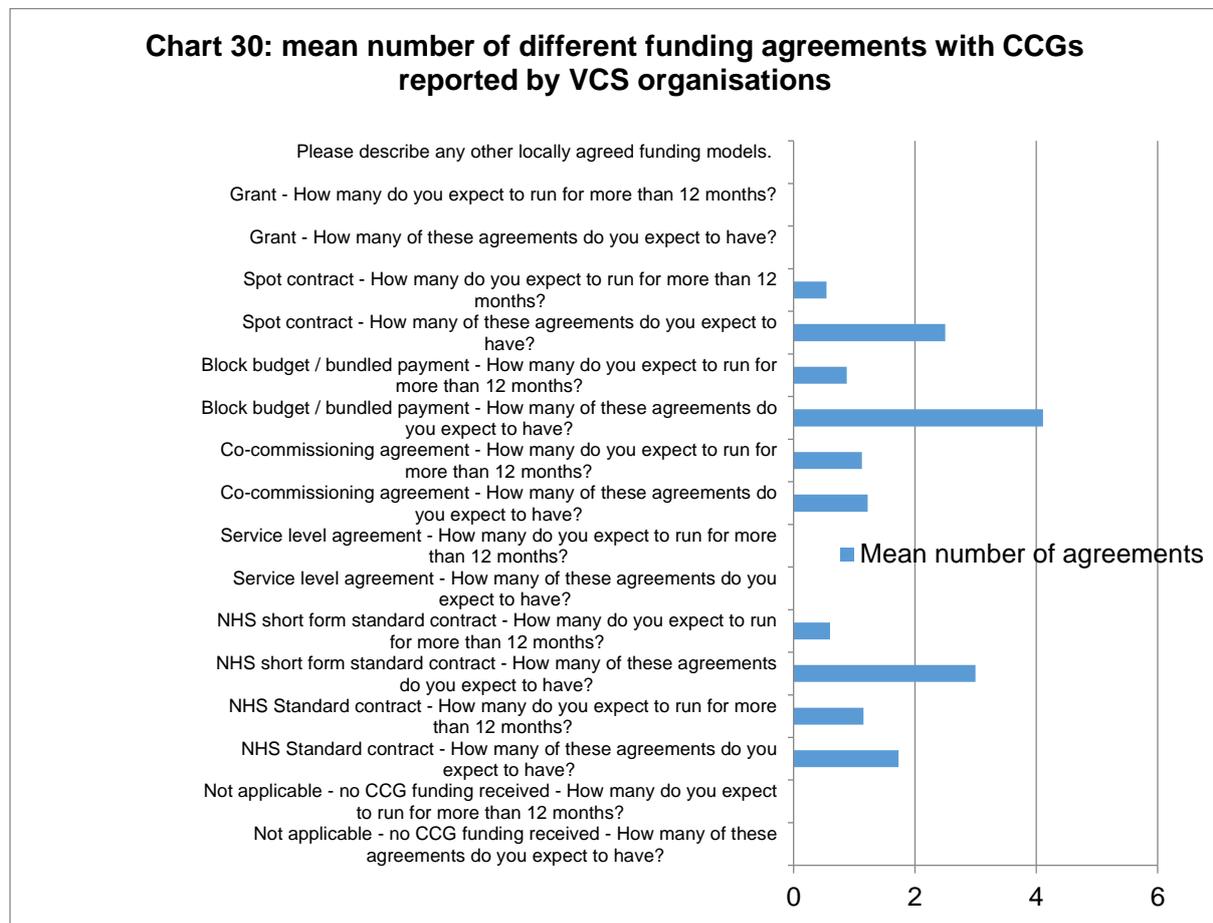
Estelle Hudson, Demelza Hospice Care for Children

We welcome the fact that charities have a mean of three NHS short form contracts each

53. NHS England introduced a new short form contract for commissioners to use with charities in 2015/16. As Chart 30 shows, this is being used.

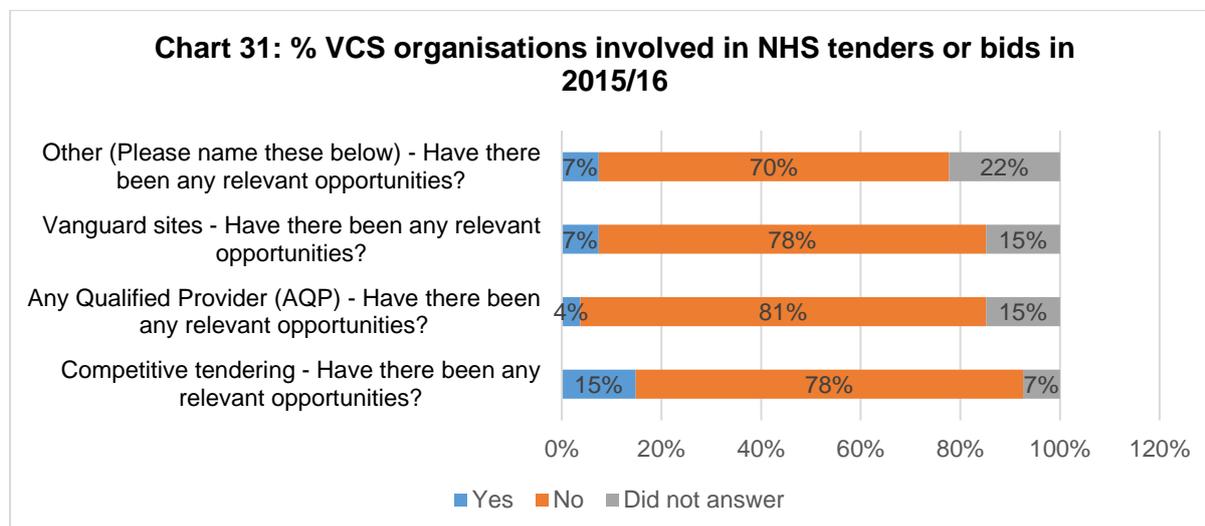
Disappointingly, however, charities have a mean of two NHS standard contract agreements each

54. As highlighted by Chart 30, this is a concern given the extra burden the standard contract can place on charities in comparison to the proportion of care costs met by CCG funding.



A minority of charities have been involved in NHS tenders or bids in 2015/16

55. As Chart 31 shows, very small proportions of respondents have been involved in NHS tenders or bids in 2015/16. This is a similar response to 2014/15.



A majority of VCS provider organisations are partnering with other organisations to deliver services

56. Chart 32 shows that 56% of our respondents report that they are working with others to deliver services. 41% are working together on fundraising.

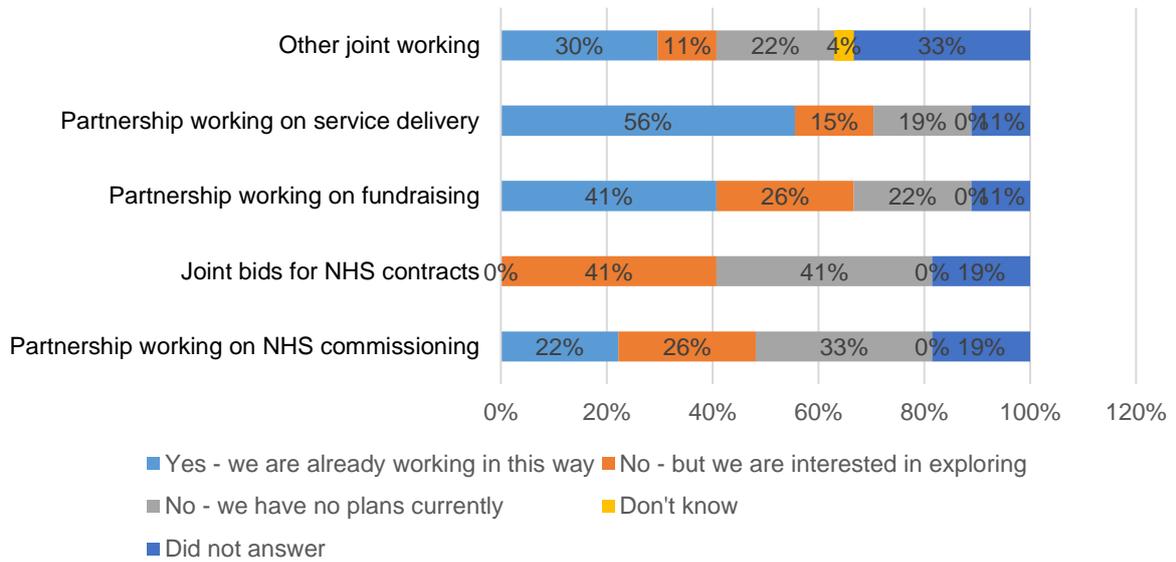
“Statutory agencies are seeing their budgets tightening and we provide services which benefit life limited and life threatened children and young people. We aim to work more closely in partnership with commissioners, rather than a wholly commissioner/provider relationship. Most commissioners are willing to engage and look at the potential, although some have not even responded to our request to meet with them. This is not only about funding, but about providing the best services for those who need them. For example, we are working in partnership with Guy's and St Thomas' NHS Trust to provide a Paediatric Palliative Care Nurse Specialist in the Evelina Children's Hospital, which is hosted and employed by the hospital trust and paid for by our hospice.”

Estelle Hudson, Demelza Hospice Care for Children

However, no VCS provider organisations are working together with others on joint bids for NHS contracts

57. Chart 32 shows that 41% of respondents are interested in exploring this option. Only 22% of VCS provider organisations are working together on joint bids for NHS contracts.

Chart 32: Is your organisation partnering with other organisations (hospices, palliative care providers, or other partners) to deliver services or secure commissioned funding?



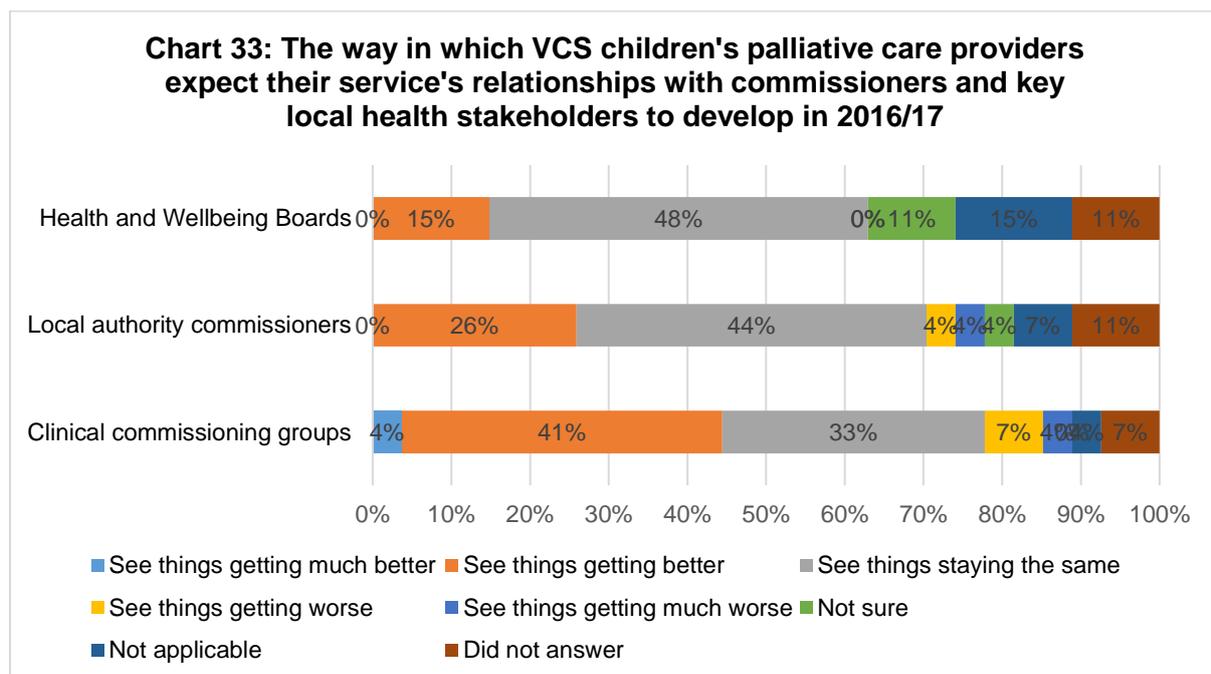
Relationships, contracts and agreements in 2016/17

Charities are slightly more optimistic about their relationships with statutory bodies than they were in 2015

58. Chart 33 shows how 45% of respondents expected their relationships with their CCGs to improve in 2016/17 compared to 2015/16. This is an increase on the 38% who expected relationships to improve between 2014/15 and 2015/16. 26% expected their local authority relationships to improve compared to 23% the year before. And 15% expected their health and wellbeing board relationships to get better, which is the same proportion as in our 2015 survey.

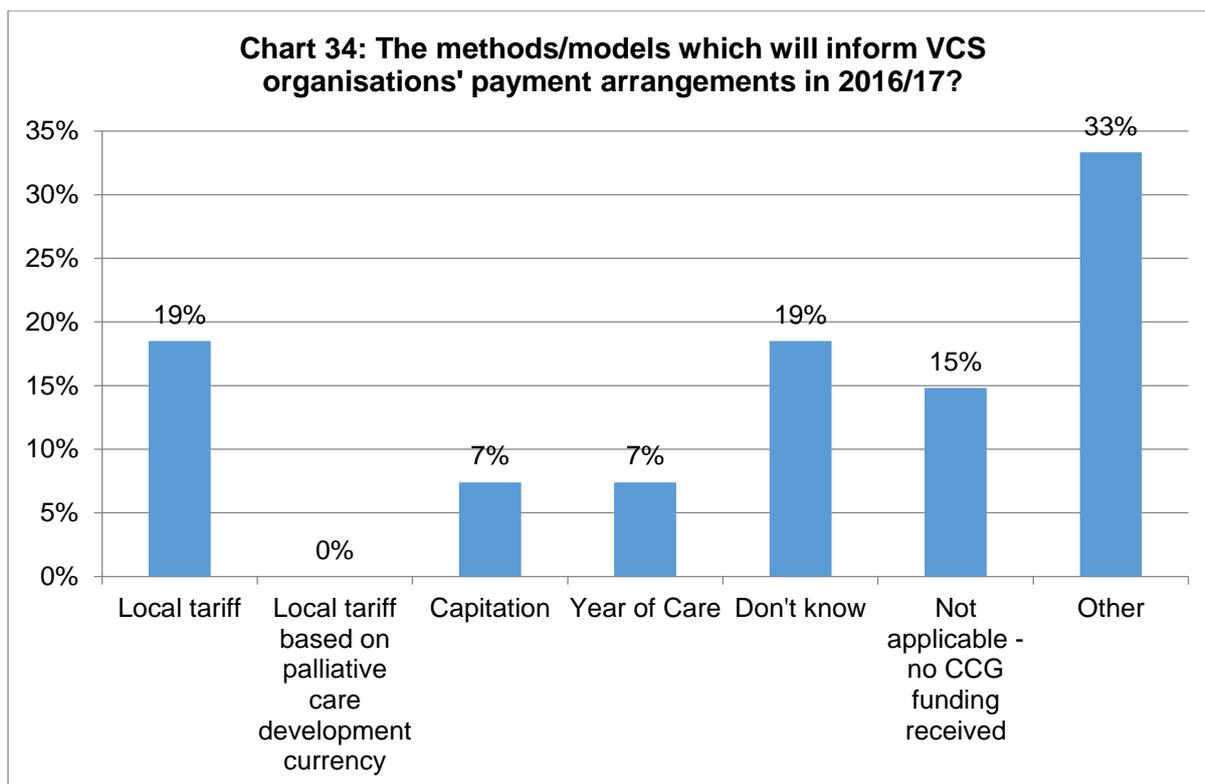
Fewer children's charities expect their relationships with statutory bodies to get worse in 2016/17

59. Chart 33 shows how 11% of respondents expected their relationships with their CCGs to get worse or much worse in 2016/17 compared to 2015/16. This is a decrease on the 19% who expected relationships to worsen between 2014/15 and 2015/16. 8% expected their local authority relationships to worsen compared to 12% the year before. And no respondents expected their health and wellbeing board relationships to get better, which is the same proportion as in our 2015 survey.



Charities expect their commissioners to use very similar funding models in 2016/17 to those which were utilised in 2015/16

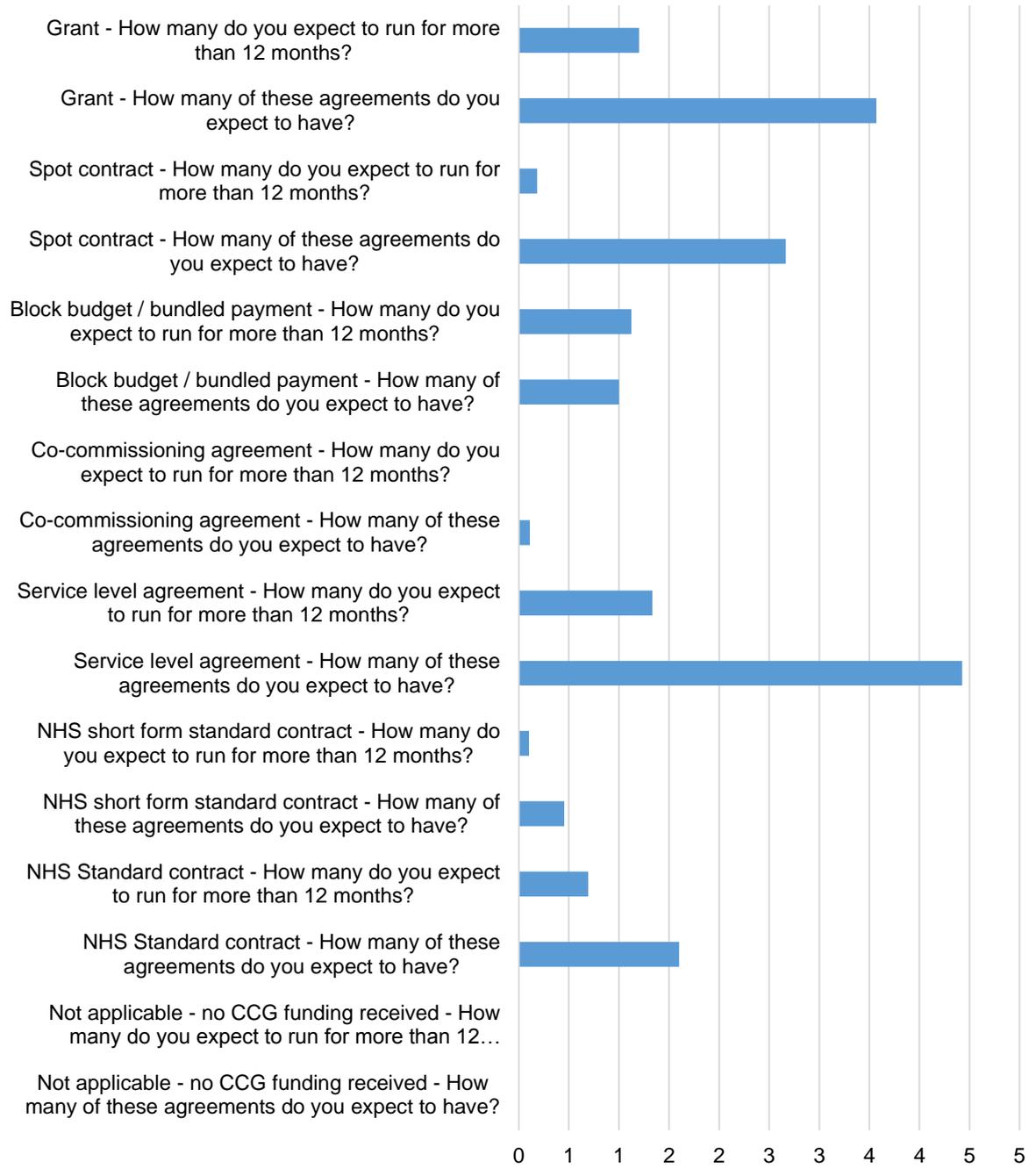
60. Chart 34 shows that the proportions of respondents which expect local commissioners to use local tariffs, capitation and year of care models are exactly the same as those which reported these methods being used in 2015/16. Again, no respondents expect the palliative care currency to be used in 2016/17.



Charities expect more service level agreements and grants in 2016/17 – but the same number of standard contracts

61. Our respondents expect to have a mean of five service level agreements and four grant agreements each in 2016/17. They had none of each in 2015/16. They also expect the same number of mean NHS standard contracts each (2) in 2016/17 as they received in 2015/16 (see Chart 35).

Chart 35: The mean number of funding agreements which VCS organisations expect to have with their CCGs in 2016/17



“We cannot assume any funding from any CCG as it is all based on which children require a service. I hope that the figure is similar to last year, but have absolutely no guarantees.”

A children’s hospice

Further reading

- Department for Health, NHS England, Public Health England. 2016. Review of partnerships and investment in the voluntary sector. Available to download at: <http://bit.ly/1XBY5jx>
- Department of Health. 2016. Our Commitment to you for end of life care: The Government Response to the Review of Choice in End of Life Care. Available to download from: <http://bit.ly/29GwFsD>
- Hughes-Hallett T, Craft A, Davies C. 2011. Palliative Care Funding Review: Funding the Right Care and Support for Everyone - Creating a Fair and Transparent Funding System; the Final Report of the Palliative Care Funding Review – An Independent Review for the Secretary of State for Health. Available to download at: <http://bit.ly/15mBe4u>
- NHS England. 2015. Developing a new approach to palliative care funding. Available to download from: <http://bit.ly/2fHMku3>
- Together for Short Lives. 2016. Commissioning children's palliative care in England: The results of Together for Short Lives' freedom of information requests of NHS clinical commissioning groups (CCGs) and local authorities in England. Available to download from: www.togetherforshortlives.org.uk/datamap
- Together for Short Lives. 2013. A Core Care Pathway for Children with Life-Limiting and Life-threatening Conditions. Available to download from: <http://bit.ly/18Vd3JV>
- Together for Short Lives. 2015. Jointly commissioning palliative care for children and young people. A resource to support clinical commissioning groups (CCGs) and local authorities in England to effectively commission palliative care for children and young people aged 0–25. Available to download from: www.togetherforshortlives.org.uk/jointcommissioning