

Statutory funding for voluntary sector children's hospice and palliative care providers in 2016/17

A briefing from Together for Short Lives

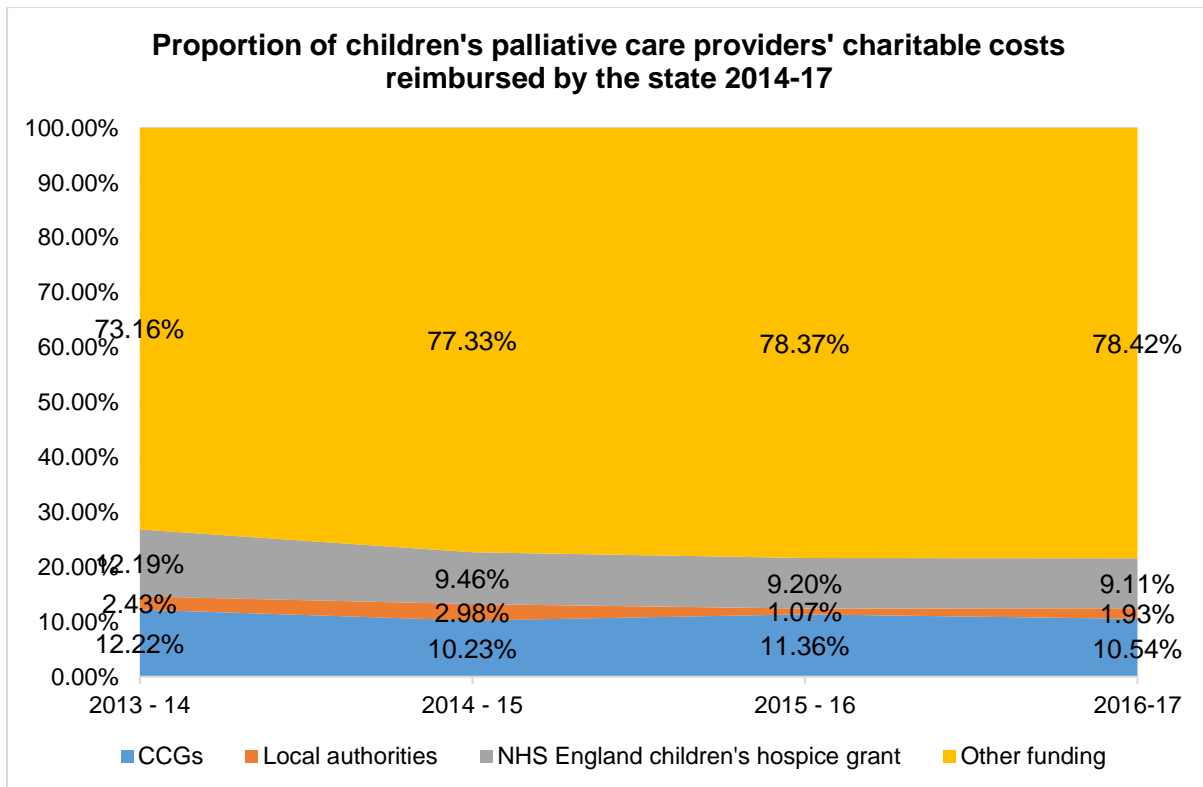
Introduction

1. This briefing sets out what Hospice UK and Together for Short Lives found when we jointly surveyed children's hospices and other voluntary sector children's palliative care providers in England about their statutory funding and commissioning arrangements.
2. This is the third year running in which we have worked jointly to survey these organisations with a view to understanding:
 - how much money they receive from statutory sources
 - the complexity of these arrangements
 - how they are impacted by changes in statutory funding.
3. As such, our survey is an important indicator of how fair, sustainable and transparent statutory funding for hospice and palliative care providers was across England in 2016/17 - and the extent to which they expected this to the case in 2017/18.
4. 29 voluntary sector children's palliative care providers responded to our survey. Of these, 28 are children's hospice organisations which 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 29 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.

Our detailed findings

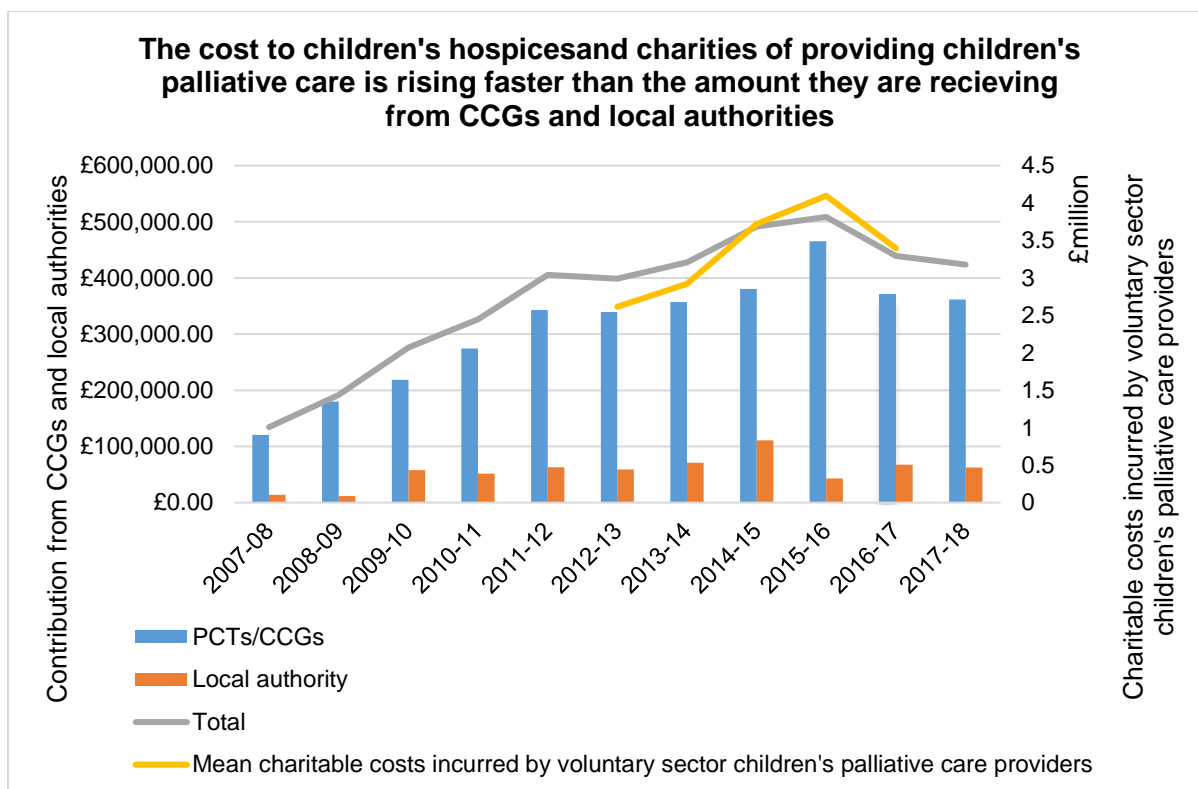
The state is failing to contribute enough to the children's palliative care provided by children's hospices and other children's palliative care charities in England - and this shows little sign of improving

5. The state's total contribution to the charitable expenditure incurred by all of our respondents combined remained, at 22% in 2016/17, which is the same as 2015/16 and below the 23% recorded in 2014/15 and 27% in 2013/14.



CCGs are contributing less to children's hospices and other children's palliative care charities

6. The 22% contribution from the state comprises contributions from CCGs, local authorities and NHS England (through the Children's Hospice Grant). In total, we have found that CCGs contributed 10.6% to the charitable expenditure incurred by all of our respondents combined during 2016/17. This is a slight fall on the 11.3% which we recorded in 2015/16.
7. As chart (number) demonstrates below, overall, CCGs are contributing significantly less to charities in cash terms. In 2016/17, each charity received a mean of £361,407 from their local CCGs, which is a 20% fall compared to the £465,500 provided in 2015/16. This fall has been mirrored by a decrease in the amount of money which charities are spending on children's palliative care; their charitable expenditure was 17% less in 2016/17 (£3,397,787.82) compared to 2015/16 (£4,098,103.00).
8. We know that the number of babies, children and young people with life-limiting and life-threatening conditions - and therefore the demand for children's palliative care - is growing year on year. Therefore, we conclude that some charities are being forced to reduce their expenditure in response to this reduction in CCG funding.



Children's hospices and palliative care charities are funded by a varied number of CCGs and local authorities

9. Children's hospices and charities have varied and mixed funding relationships. One charity is funded by 15 CCGs, while three receive funding from 14 CCGs. The most common number of CCGs which fund charities (the mode) is one, which is reported by six (21%) of charities.
10. Charities receive funding from a mean of two local authorities each. One charity is funded by eight local authorities. The most common number of local authorities which fund charities (the mode) is one, which is reported by 12 (41%) of charities.

Local authority funding has risen slightly, but still does not reflect the social care provided by children's hospices and other children's palliative care charities

11. Overall, local authorities contributed just 1.9% to charitable expenditure (a modest rise on the 1.1% recorded in 2015/16). They also contributed more in cash terms, providing a mean of £67,653.71 per charity in 2016/17, compared to £43,095.24 provided in 2015/16.
12. Despite this very small rise, local authority funding for children's hospices and other children's palliative care charities does not adequately reflect the amount of local care and support provided to children with life-limiting conditions. It is shocking that 11 (44%) of the children's hospices and other children's palliative care charities report receiving no money whatsoever from their local authorities. Local authorities are responsible for planning and funding services like short breaks for respite, bereavement care and counselling. Without the services provided by charities, seriously ill children and their families would be forced to rely on other overstretched services, having a greater negative impact on the public purse.

Changes in statutory funding is having a negative impact on children with life-limiting conditions and their families

13. As chart (number) shows below, this is corroborated by the fact that children's hospices and other children's palliative care charities report that the changes in statutory funding they have experienced had a negative impact on the majority of services which they offered to seriously ill children and their families during 2016/17.

"By failing to secure any CCG grant we have been unable to develop our service to meet the growing demand."

Andrew Rice, Finance Manager, Alexander Devine Children's Hospice Service

14. For example, 7 (24%) of respondents stated that changes had a negative or somewhat negative impact on end of life care services for children, compared to 4 (14%) which reported that they had a positive or somewhat positive impact.

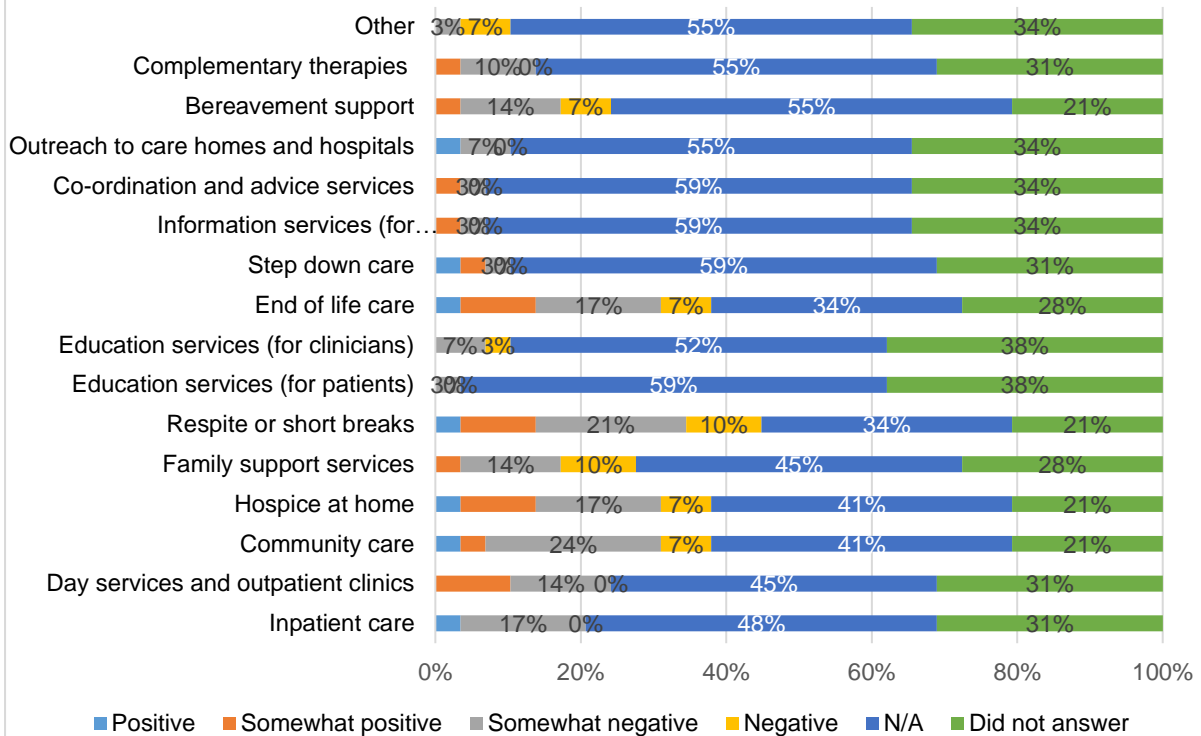
"One local authority no longer funds the short breaks activities they previously commissioned, so these have stopped."

A children's hospice organisation

15. 9 (31%) respondents reported that changes had a negative or somewhat negative impact on provision of short breaks (respite) services for children, compared to 4 (14%) which reported that they had a positive or somewhat positive impact. This is particularly worrying in the context of research conducted by [Julia's House Children's Hospice and Bournemouth University](#), which found that 64% of divorced or separated parents cited having a child with complex needs as a reason for the breakdown of their relationship. Of those couples, 75% had no access to short breaks at that time.
16. 9 (31%) respondents reported that changes had a negative or somewhat negative impact on community care, compared to 4 (14%) which reported that they had a positive or somewhat positive impact. 7 (24%) respondents reported that changes had a negative or somewhat negative impact on hospice at home, compared to 4 (14%) which reported that they had a positive or somewhat positive impact. Both findings suggest that changes in statutory funding are having a negative impact on the extent to which children and families are able to choose to receive palliative care at home and in the community. In turn, this is undermining the government's end of life care choice commitment for children¹.

¹ Department of Health. 2016. 'Our Commitment to you for end of life care: The Government Response to the Review of Choice'. Available to download from: <http://bit.ly/2oOUsfj>

Have changes in statutory funding levels had an impact on the services your organisation provides?



“Statutory organisations such as CCGs and LAs have lower financial resources each year and therefore all negotiations for funding become increasingly more involved and time-consuming.”

Hazel Ryan, Statutory Partnerships Manager, Richard House Children's Hospice

“The demand for end-of-life care has increased notably in the last two years and we currently have insufficient resource to meet both this demand and maintain previous levels of continuing care.”

Sam Loveday, Director of Income Generation, East Anglia's Children's Hospices

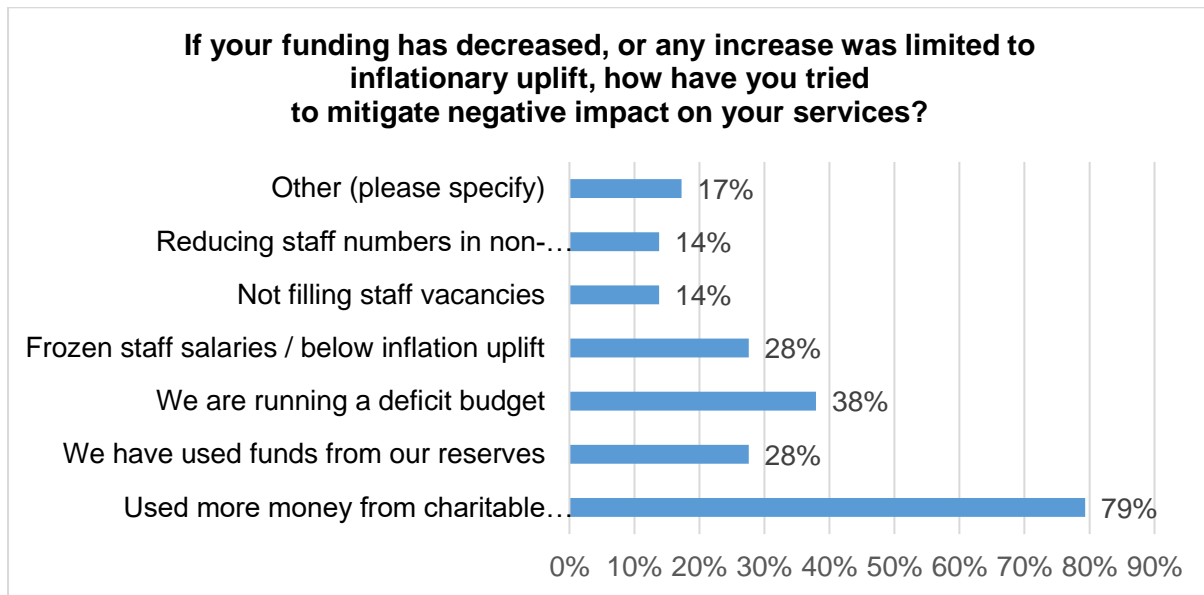
“Gradual gross and net impact of incremental NHS cost/grant reductions has reduced staff numbers & reduced patient activity.”

Jill Gregory, Finance Director, St Oswald's Hospice

Where statutory funding has decreased, children's hospices and other children's palliative care charities are being forced to find more money from charitable sources

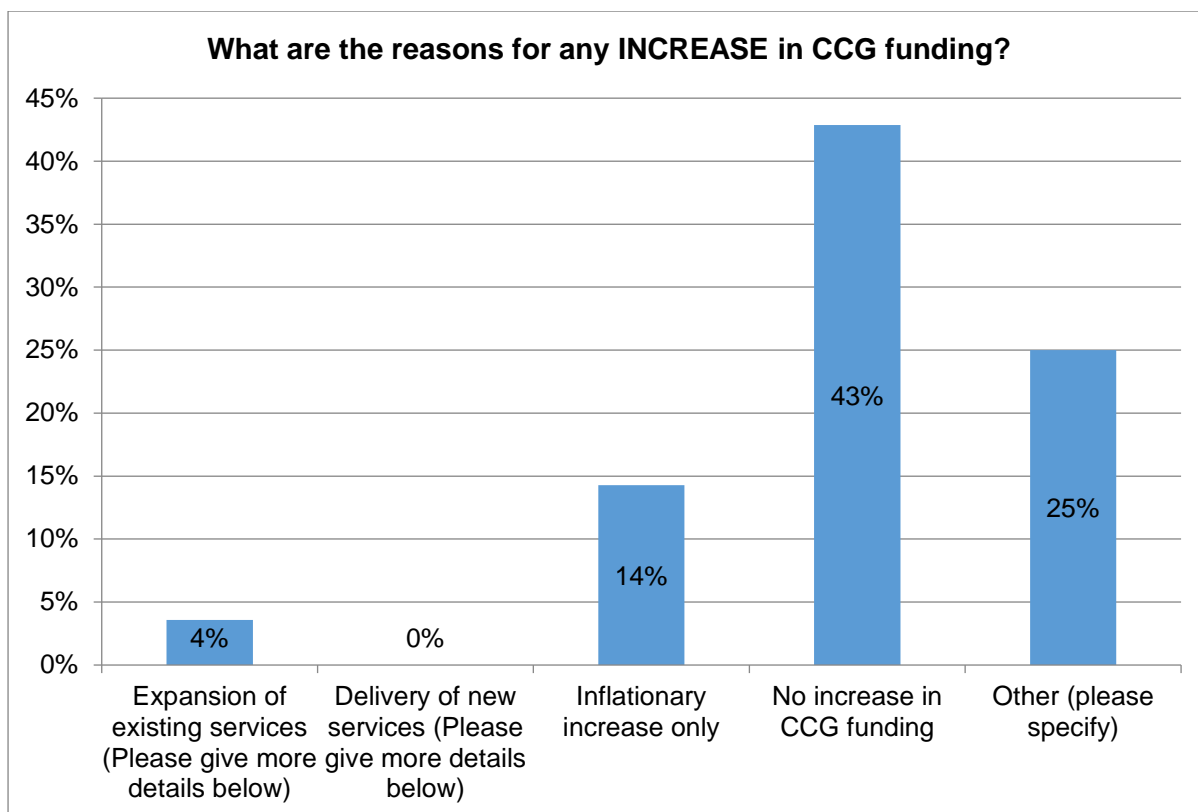
17. Where children's hospices and other children's palliative care charities have experienced falls in statutory funding, 23 (79%) report that they have been forced to find more money from charitable sources to fund their services. 11 (38%) are running a

deficit budget, while eight (28%) are using funds from reserves. Eight also report that they have frozen staff salaries or offered pay rises below the rate of inflation.



Why has statutory funding for children’s hospices and other children’s palliative care charities changed?

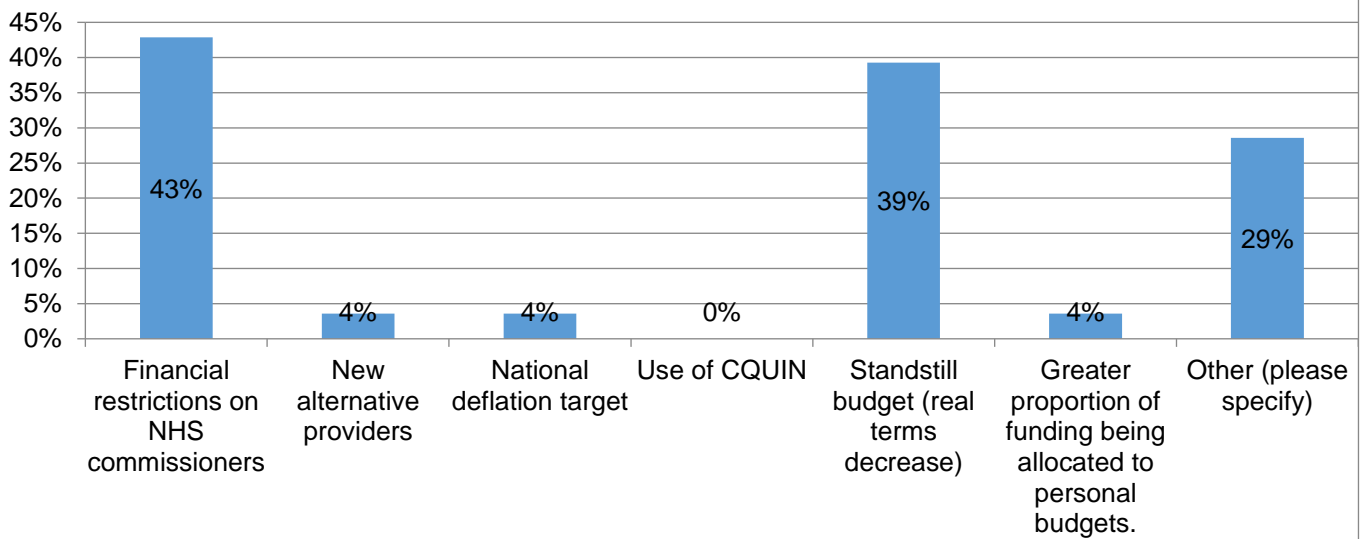
18. Nearly half (12, 43%) of respondents stated that their CCG funding did not increase in 2016/17. Of those which did report an increase, 4 (14%) stated that this was due to an inflationary increase, while 4% stated that the rise was due to their existing services expanding.
19. In terms of other reasons, one children’s hospice service reported that during 2016-17 it had an exceptional amount of overnight care funded through spot purchasing. This was based on long stays for a very small number of children who have now been discharged. As a result, its income since has since dropped significantly.
20. Another children’s hospice service stated that it increased its tariffs for short breaks in line with inflation and introduced a new tariff for complex care.



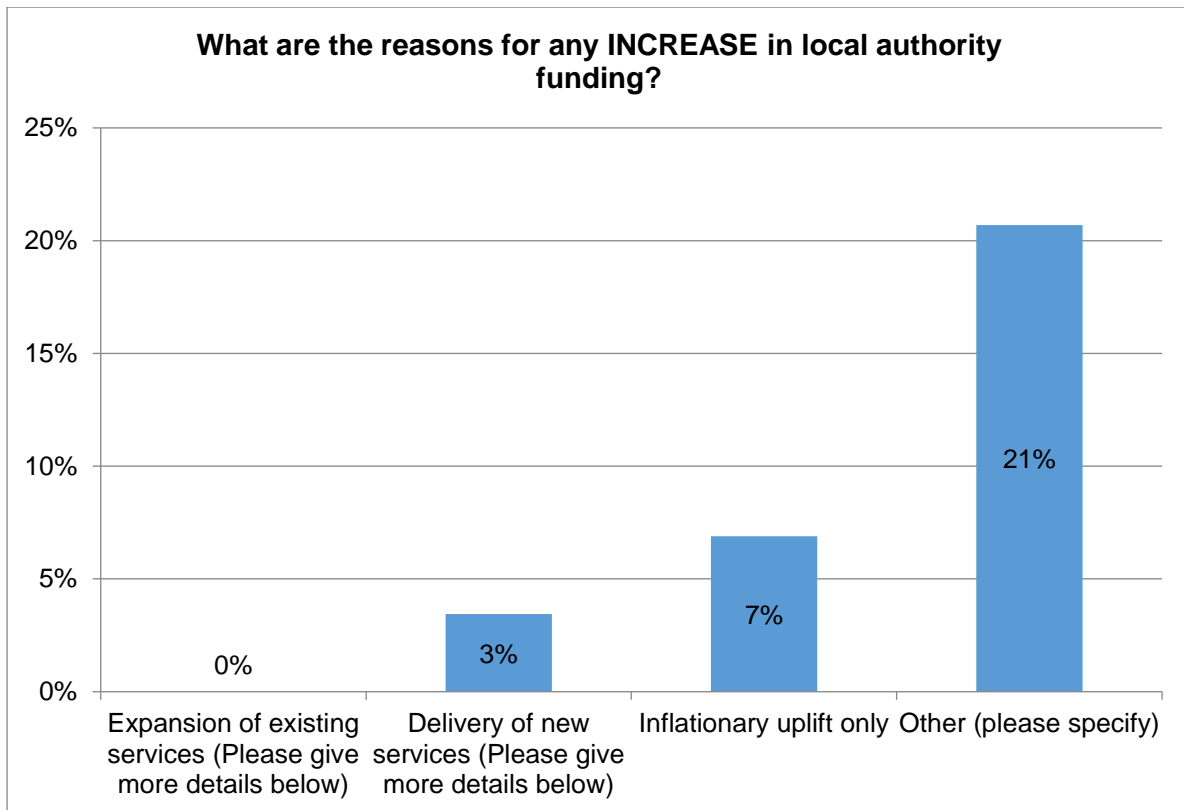
21. The most widely reported reason for CCGs decreasing or freezing their contributions to children’s hospices and other children’s palliative care charities was financial restrictions on NHS commissioners (including restricted budgets) reported by 12 respondents - – 43%). This was followed by a standstill budget (reported by 11 (39%)) and other reasons (reported by eight (29%)). Other reasons included:

- CCGs reducing their spending because they did not require a placement for a specific child
- It is increasingly hard to secure individual funding agreements for young adults with life-limiting conditions.
- Funding agreements for new patients are harder to secure and often of lower value than those for longer-standing patients (with pre-existing agreements).

What are the reasons for any DECREASE or STANDSTILL in CCG funding for 2016/17 (excluding capital grants)

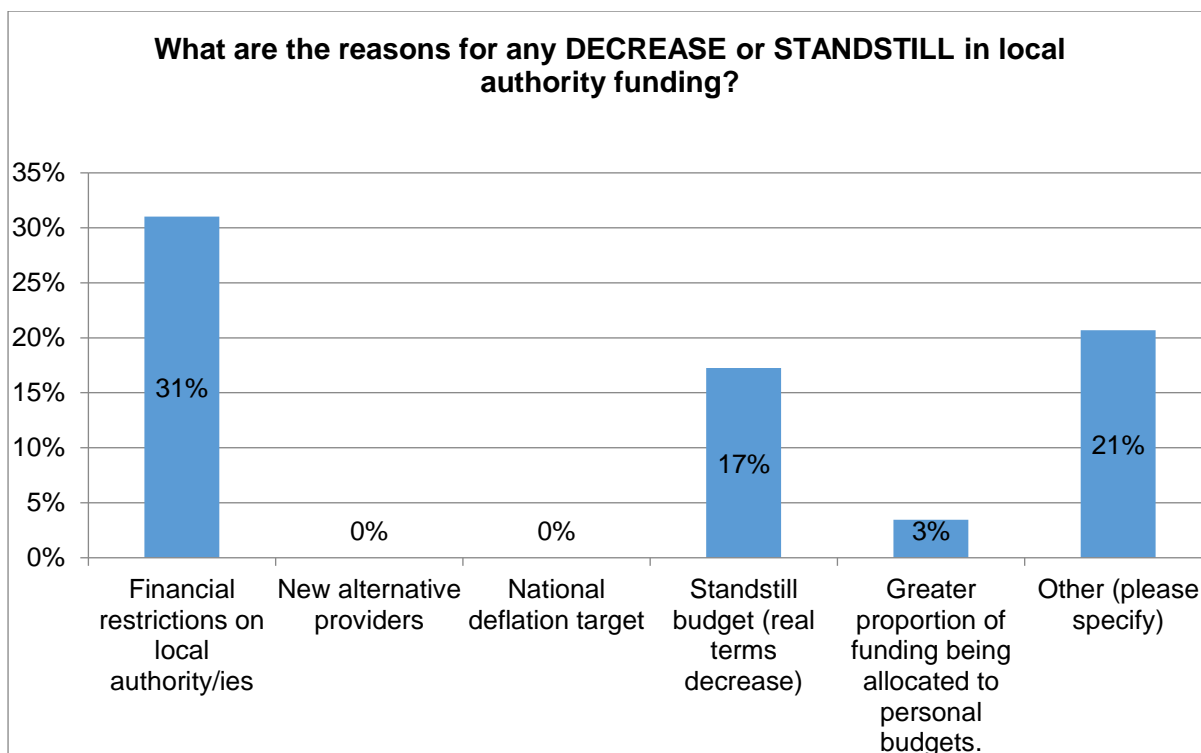


22. Those children’s hospices and other children’s palliative care charities which received more money from local authorities in 2016/17 did so as a result of a wide range of factors. These included greater numbers of spot purchases from local authorities. Two (7%) charities reported that they received more due to an inflationary uplift from councils, while just one (3%) stated that their rise was due to them delivering new services.



23. Nine (31%) of the children’s hospices and other children’s palliative care charities which experienced a drop in their local authority funding did so because of financial restrictions on the authority. Five (17%) cited a standstill budget, while six (21%) cited a variety of other reasons. These included:

- local authorities in general being reluctant to pay the price for overnight specialist palliative care.
- the priced for contracted delivery at a lower amount than previous grant
- increasing difficulty in securing individual funding agreements for young adults and for other new patients
- local authorities reducing allocations and funded entitlements to children and young people for social short breaks for respite
- inflexible service specifications.



Children’s hospice grant continues to be a vital source of funding

24. This year’s survey again emphasised how important the NHS England Children’s Hospice Grant is to children’s hospice organisations; among the 27 who answered this question, the grant, on average, contributed 9.1% of their charitable expenditure in 2016/17.

No children’s hospice or other children’s palliative care charity reports that their clinical commissioning groups are using the NHS children’s palliative care currency to determine how much funding they receive

25. There is little evidence so far to suggest that the NHS children’s palliative care funding currency², published in 2017, is having an impact on statutory funding. Indeed, no children’s charities report that their CCGs are using it.

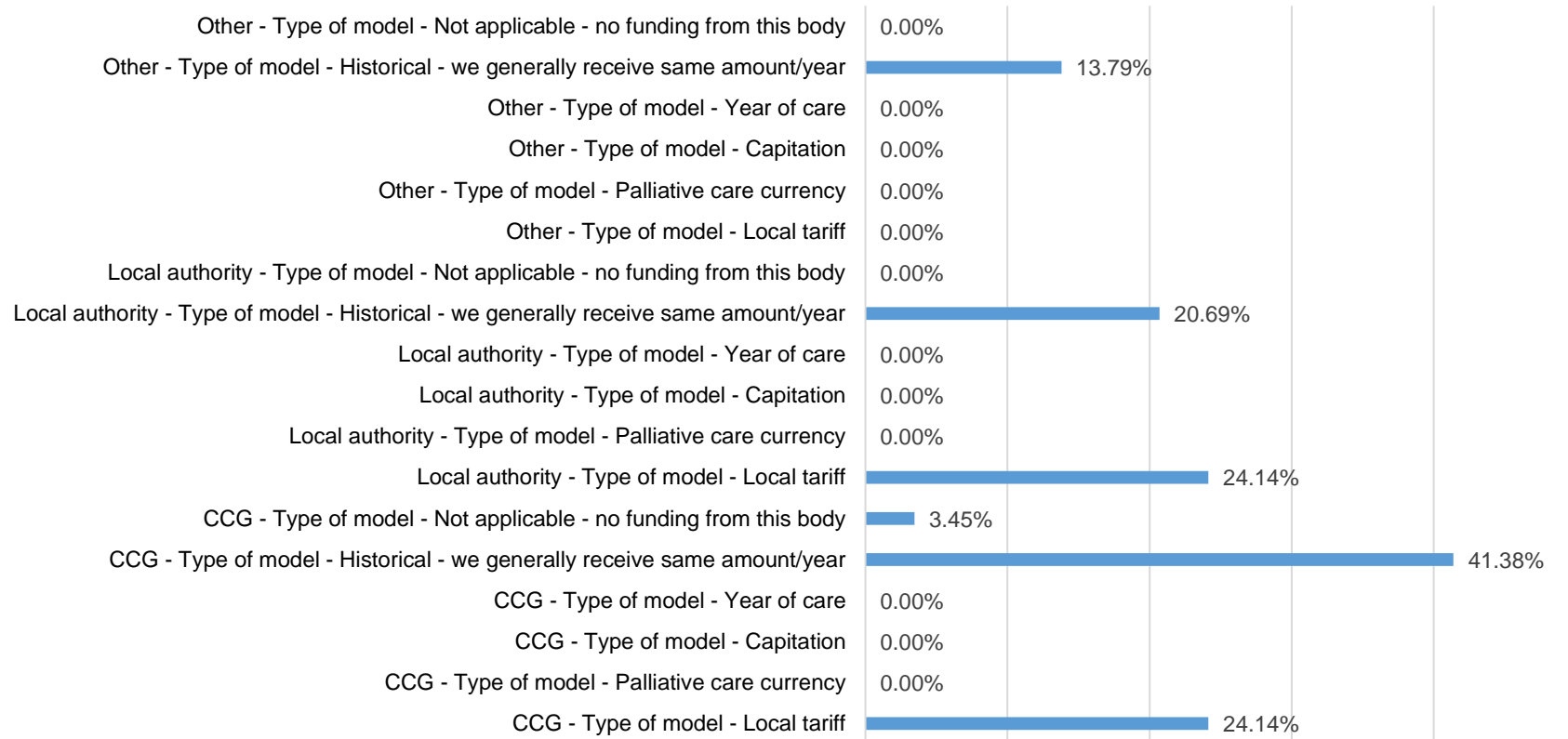
26. As chart (number) below demonstrates, 12 children’s hospices and other children’s palliative care charities (41%) report that their CCGs determine how much funding they are going to provide them with based on what they have been given in the past. Six respondents (21%) told us that their local authorities base their funding allocations on this method too. This is opposed to CCGs and local authorities using other funding models such as currencies (like the palliative care currency), capitation³ or year of care⁴ approaches.

² NHS England. 2017. Palliative Care Currency. Available to download from: <https://www.england.nhs.uk/resources/pay-syst/development/palliative-care-development-currency/>

³ HM Government. 2015. Capitation: An Introduction. Available to download from: <https://www.gov.uk/guidance/capitation>

⁴ NHS Year of Care Partnerships. Available to download from: <https://www.yearofcare.co.uk/>

How levels of statutory funding from CCGs and local authorities were determined in 2016/17



Some charities would like to use the simpler shorter form NHS standard contract, yet are being refused by their CCGs

27. Despite the fact that the more proportional shorter form contract is available for CCGs to use when commissioning charities to provide health services, four charities (14%) report that their CCG declined to use it. Two (7%) state that their CCGs have told them that they do not use the shorter form contract. One (4%) reports that their CCGs were not aware of the shorter form.

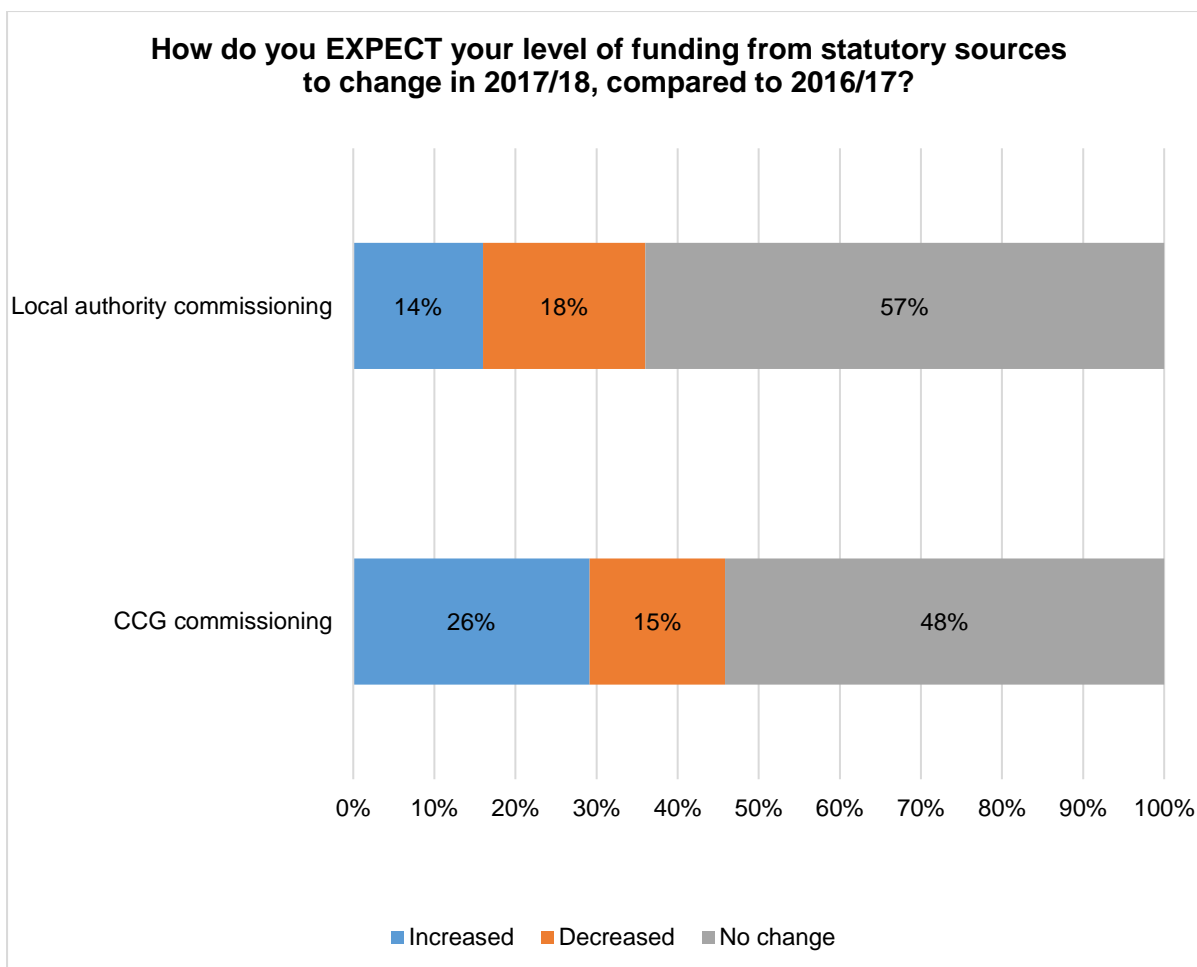
Future funding for children's hospices and other children's palliative care charities shows little signs of improving

28. Children's hospices and other children's palliative care charities report that they do not expect their statutory funding to improve significantly over the course of 2017/18. Mean funding per respondent from CCGs in 2017/18 was expected to fall by 8% to £361,406.83 compared to the £371,303.30 recorded in 2016/17.

29. 17 (63%) of respondents expected their funding from CCGs to either remain static (13 (48%)) or fall (4 (15%)) in 2017/18 compared to 2016/17.

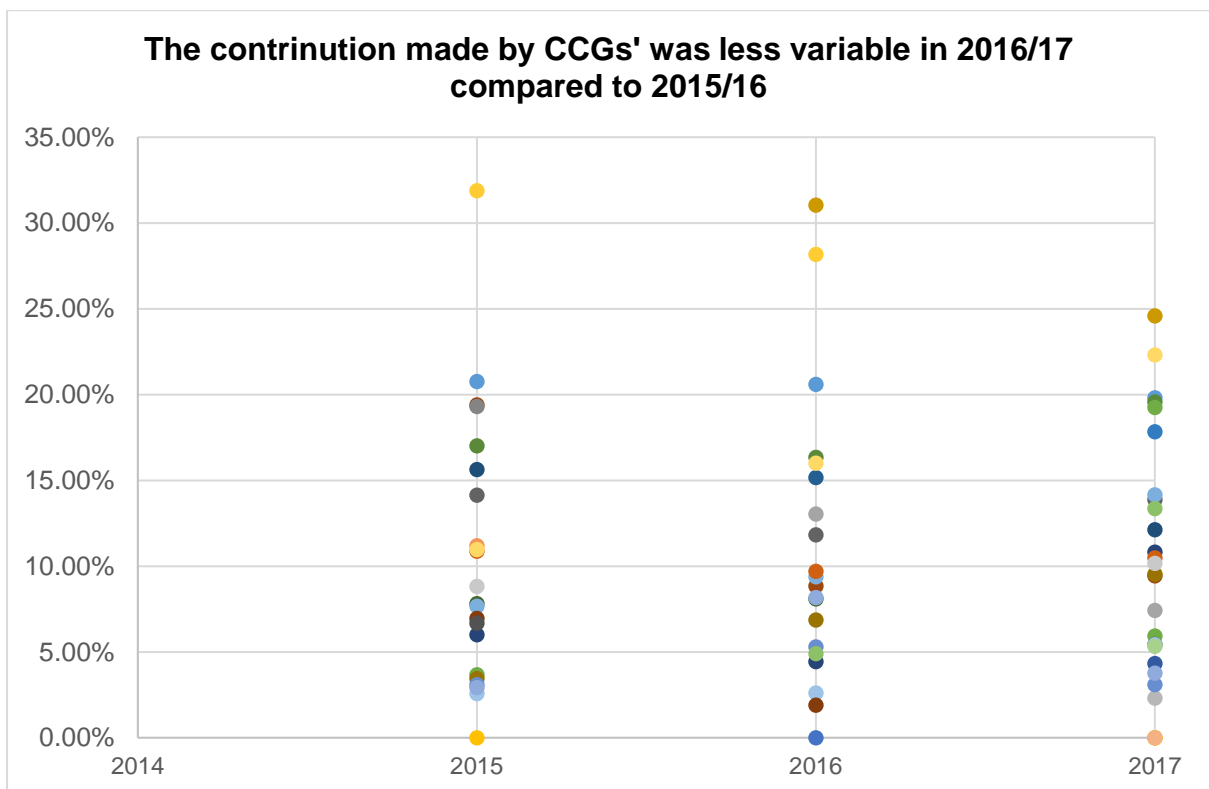
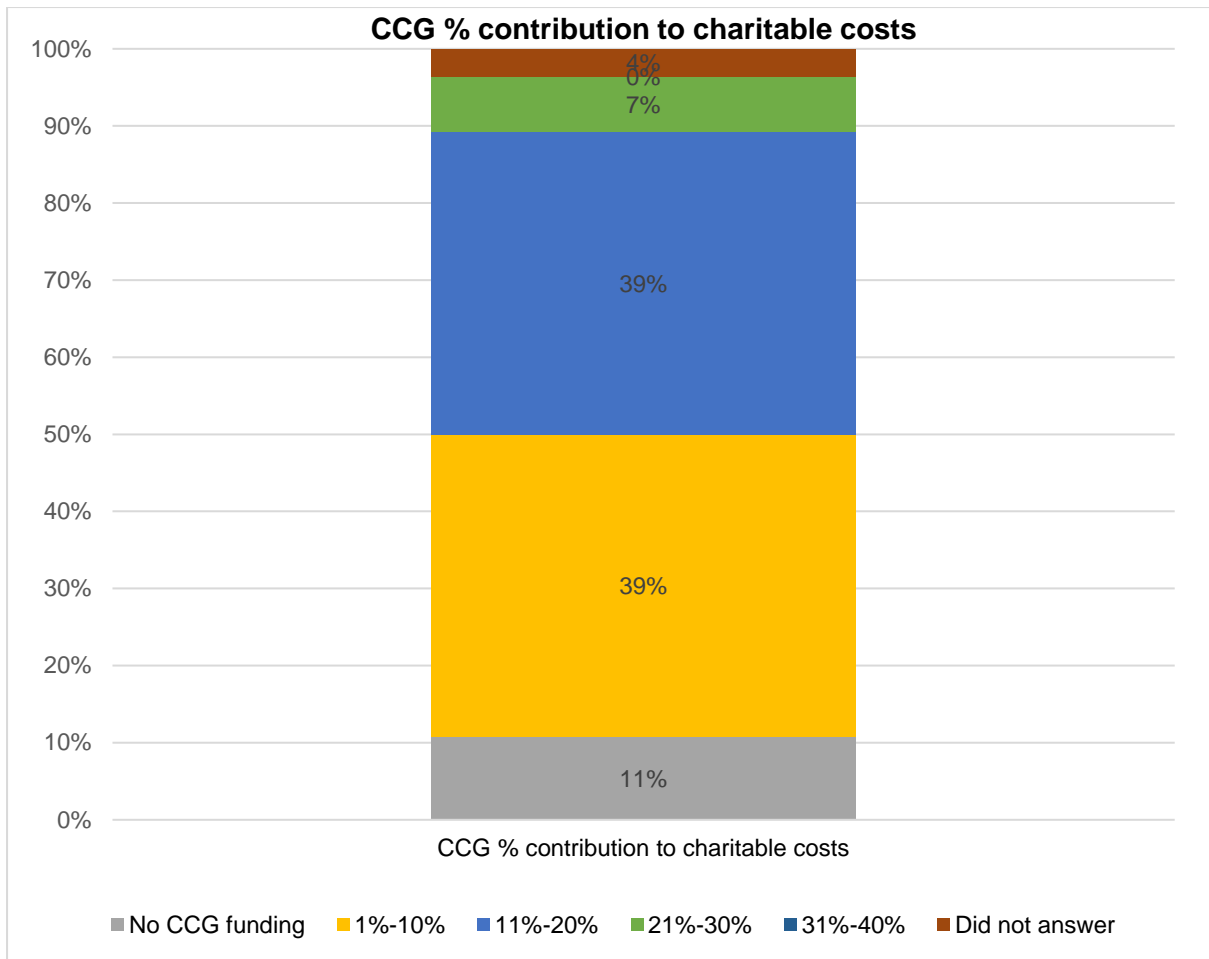
30. Mean funding per respondent from local authorities was expected to fall by 8% from the £67,653.71 recorded in 2016/17 to £62,179.72 in 2017/18.

31. 21 (75%) of respondents expected their funding from local authorities to either remain static (16 (57%) of charities) or fall (5 (18%) of charities) in 2017/18 compared to 2016/17.

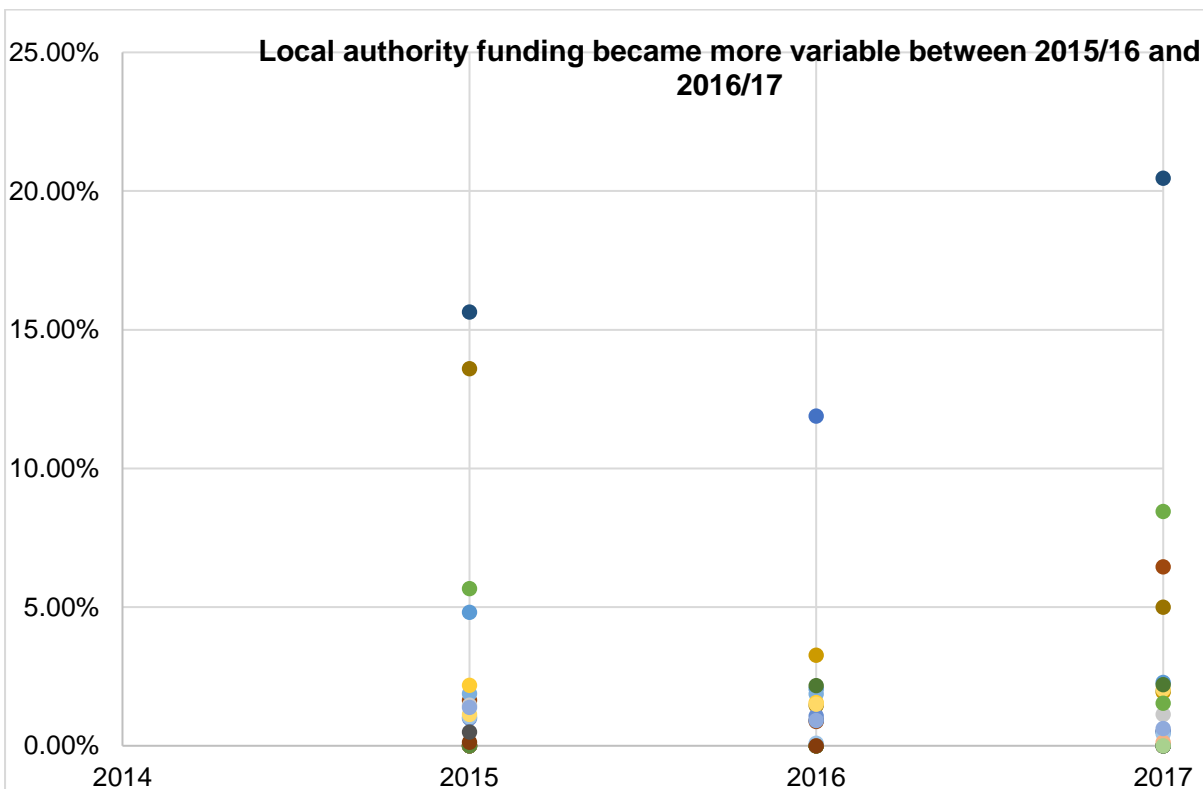
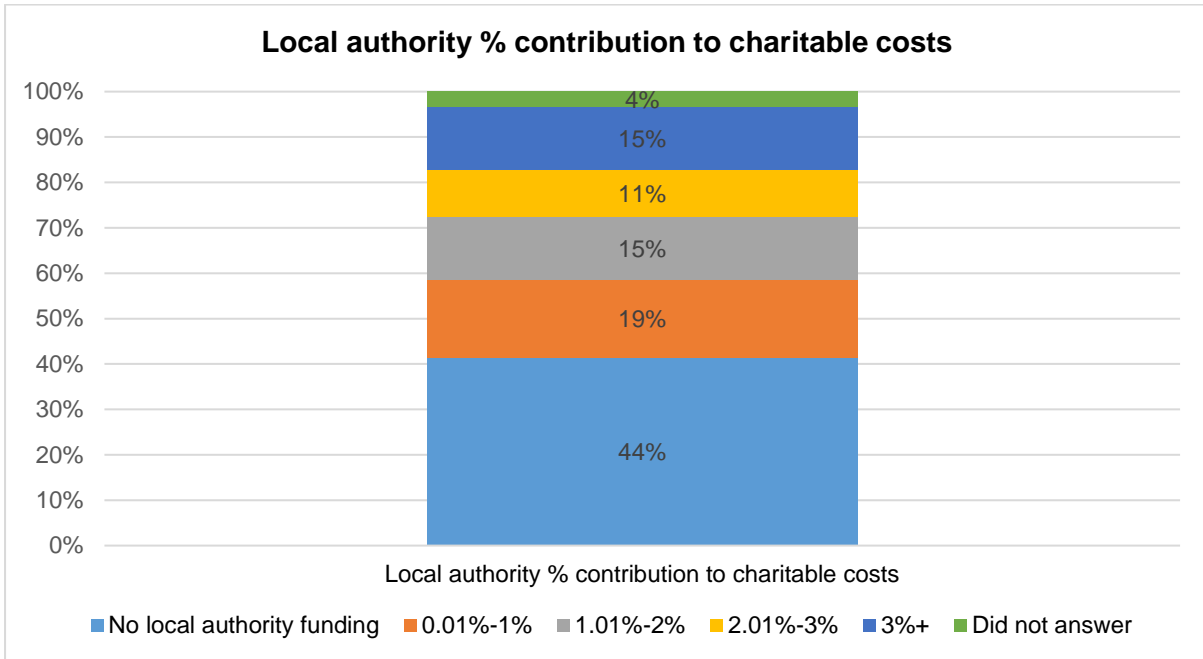


Statutory funding for children’s hospices and other children’s palliative care charities in England remains patchy

32. Overall England-wide data about the way in which the state funds children’s hospices and other children’s palliative care charities masks a wide variation in different local approaches. Calculating the standard deviation of all the percentage contributions that CCGs make to different children’s hospices and other children’s palliative care charities is a way of summarising the amount by which every contribution varies from the mean. The standard deviation in the proportion of funding which CCGs contribute to charities has dipped only slightly from 8.25% in 2015/16 to 7.11% in 2016/17. This means that CCG funding for children’s hospices and other children’s palliative care charities has become slightly less variable.
33. However, the range of contributions is large: one charity received 25% of its charitable expenditure from its local CCGs in 2016/17, while three (11%) received nothing at all. 11 children’s hospices and other children’s palliative care charities (39%) received between 1% and 10% and another 11 (39%) received between 11% and 20%.

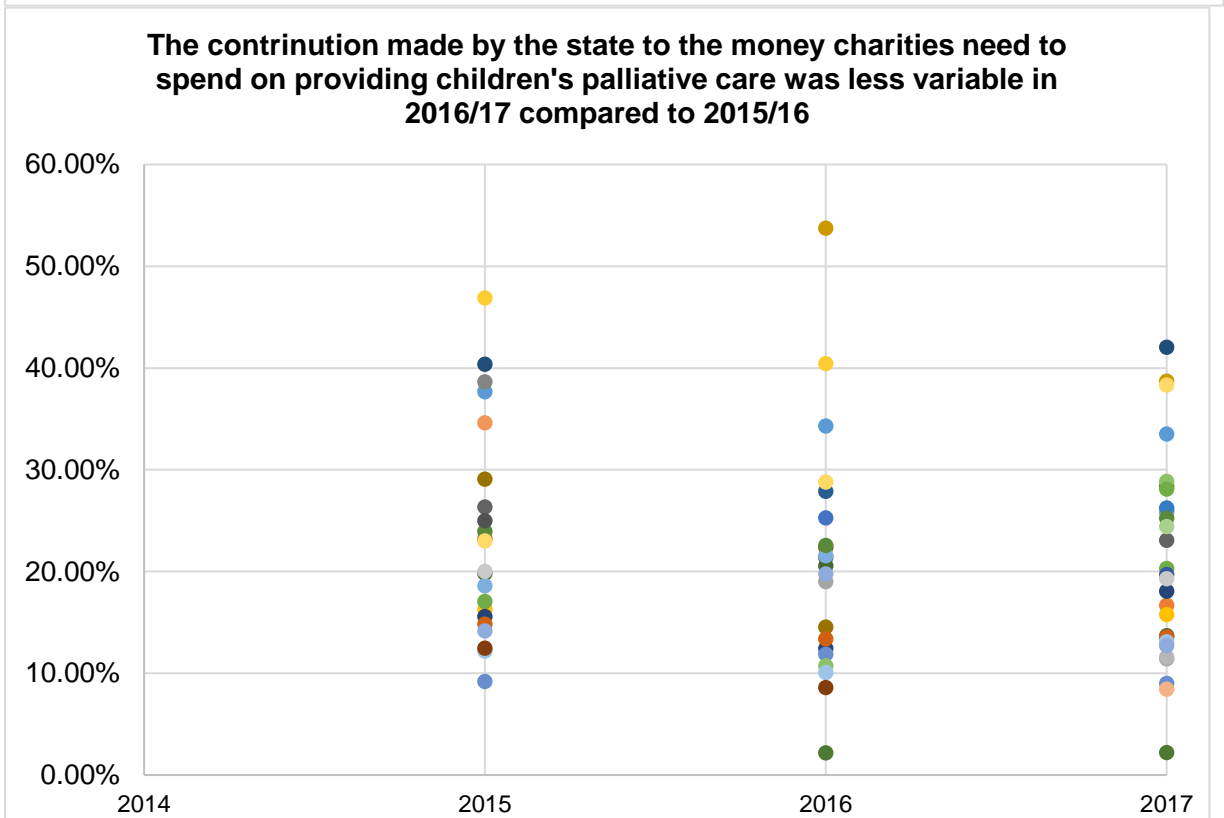
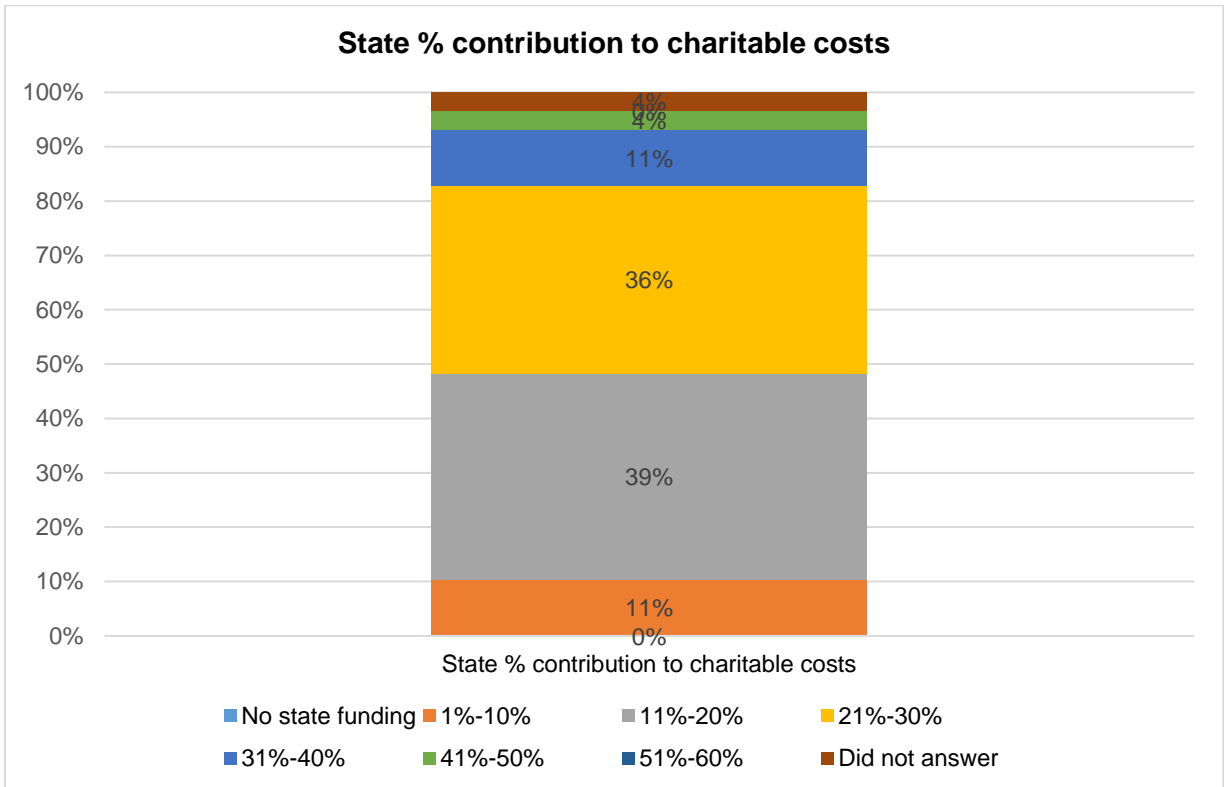


34. For local authorities, the standard deviation in their contributions to children’s hospices and other children’s palliative care charities rose from 2.58% in 2015/16 to 4.19% in 2016/17. 12 respondents (44%) received nothing from their local authorities, while one received 20% of their charitable expenditure.



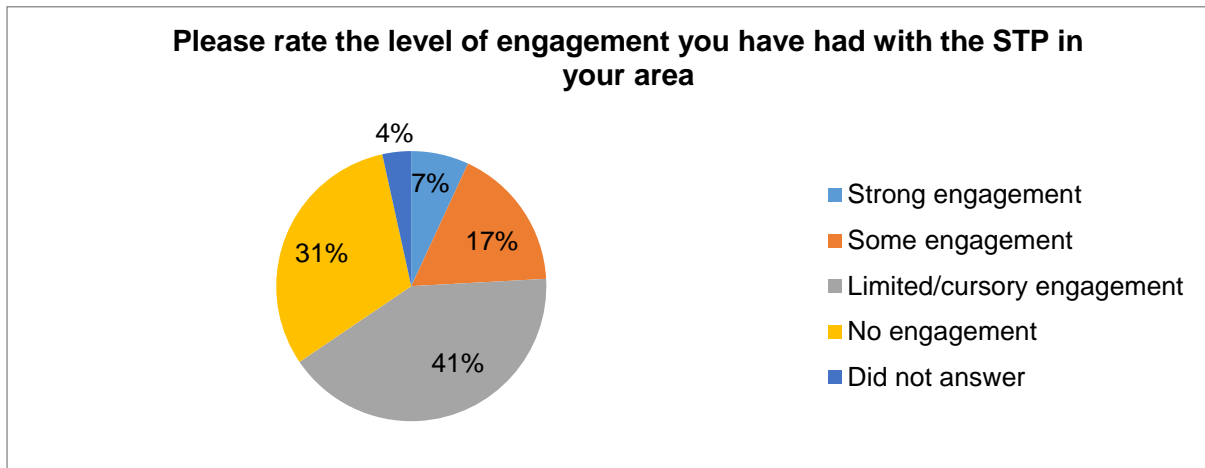
35. When the Children’s Hospice Grant is taken into account, one children’s hospice received 42% of its charitable expenditure from the state. Yet, the lowest contribution was 2%. The most common range of contributions from the state was between 11% and

20%, which was reported by 11 children's hospices and other children's palliative care charities (39%).



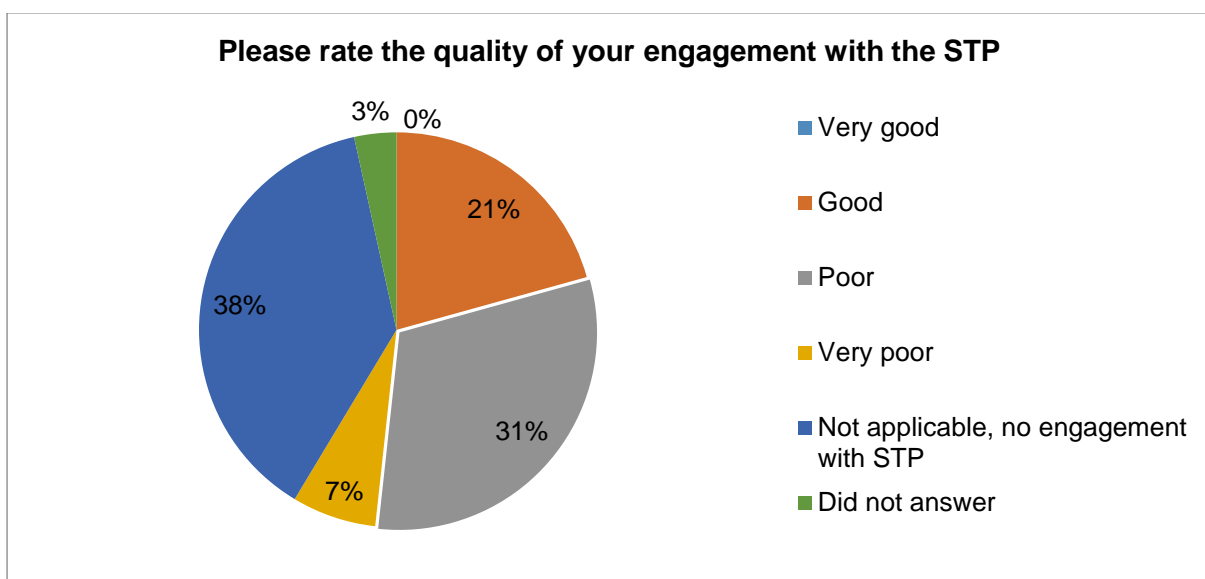
Most children’s hospices and other children’s palliative care charities have engaged with their local sustainability and transformation partnerships (STPs) – however, the quality of the engagement is largely poor

36. Only a third (nine, or 31%) of children’s hospices and other children’s palliative care charities report that they have not engaged with their local STP at all. However, limited engagement (12, or 41% of respondents) is the most widely reported, compared to five (17%) who cited some engagement and two (7%) who described strong engagement.



37. Despite this, nine (31%) describe the quality of this engagement as poor and two (7%) as very poor. Only six (21%) describe the quality of their engagement as good. No respondents describe it as very good.

38. This is particularly concerning given NHS England’s stated ambition for STPs to develop into accountable care systems (ACSs) - and eventually accountable care organisations (ACOs). Both ACSs and ACOs have potential to join-up the way in which children’s palliative care is planned, funded and provided. This could improve the extent to which health and social care is integrated around children with life-limiting conditions.



Personal budgets reimburse just 1% of the charitable expenditure incurred by our respondents

39. The NHS Mandate sets an ambitious objective that between 50-100,000 people will have a personal health budget by 2020/21⁵. Despite this, Children's charities report that personal budgets contribute just 1% of their charitable expenditure. Of those receiving personal budget income, the average number of personal budgets per charity was eight. The highest managed by any one charity was 31.

The vast majority of charities believe that they are being funded neither sustainably by the state

40. 28 respondents (97%) do not believe that their services are being funded fairly by the state. 27 (93%) do not believe that their services are being funded sustainably.

⁵ Department of Health. 2017. The Government's mandate to NHS England for 2017-18. Available to download from:
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/601188/NHS_Mandate_2017-18_A.pdf