Children’s Hospice Grant consultation:
Analysis of responses and Together for Short Lives’ recommendations
Report back to NHS England

January 2017

Background

1. Between November 2016 and January 2017, Together for Short Lives consulted children’s hospice charities in England on a potential new future formula for allocating the Children’s Hospice Grant. We consulted all current recipients of the grant. We did so on behalf of NHS England, which is responsible for administering the grant.

2. The consultation period ran from 28 November 2016 to 20 January 2017. Children’s hospice charities responded primarily through a SurveyMonkey electronic survey, although some provided written submissions. The consultation was hosted at www.surveymonkey.co.uk/r/childrenshospicegrantsurvey

3. The original deadline for responses was 5pm on Friday 6 January 2017. This was however extended to 9am on Friday 20 January 2017 to give respondents more time to source data and consider responses. 34 children’s hospice charities either fully or partially completed the survey, representing 94% of the 36 charities which receive the grant. The rate of response varied according to each question; the rate of response for each question is set out below in the ‘Question by Question’ analysis.

4. The paper below is set out in two sections:

    i. Summary of responses and Together for Short Lives’ recommendations to NHS England.

    ii. Question by question analysis of responses.

5. Annex A sets out the different options for allocating the grant which we consulted children’s hospice charities on.

6. Annex B sets out the broader context of children’s palliative care funding in England.

7. Annex C sets out the full responses we received from each charity and is attached with this report.

I. Summary of responses and Together for Short Lives' recommendations to NHS England

The size of the grant

What children's hospice charities have told us

8. It is clear from the evidence we have received from children's hospice charities and through other supporting materials (see Annex B) that the total amount of funding available through the Children's Hospice Grant is valued greatly but is also inadequate.

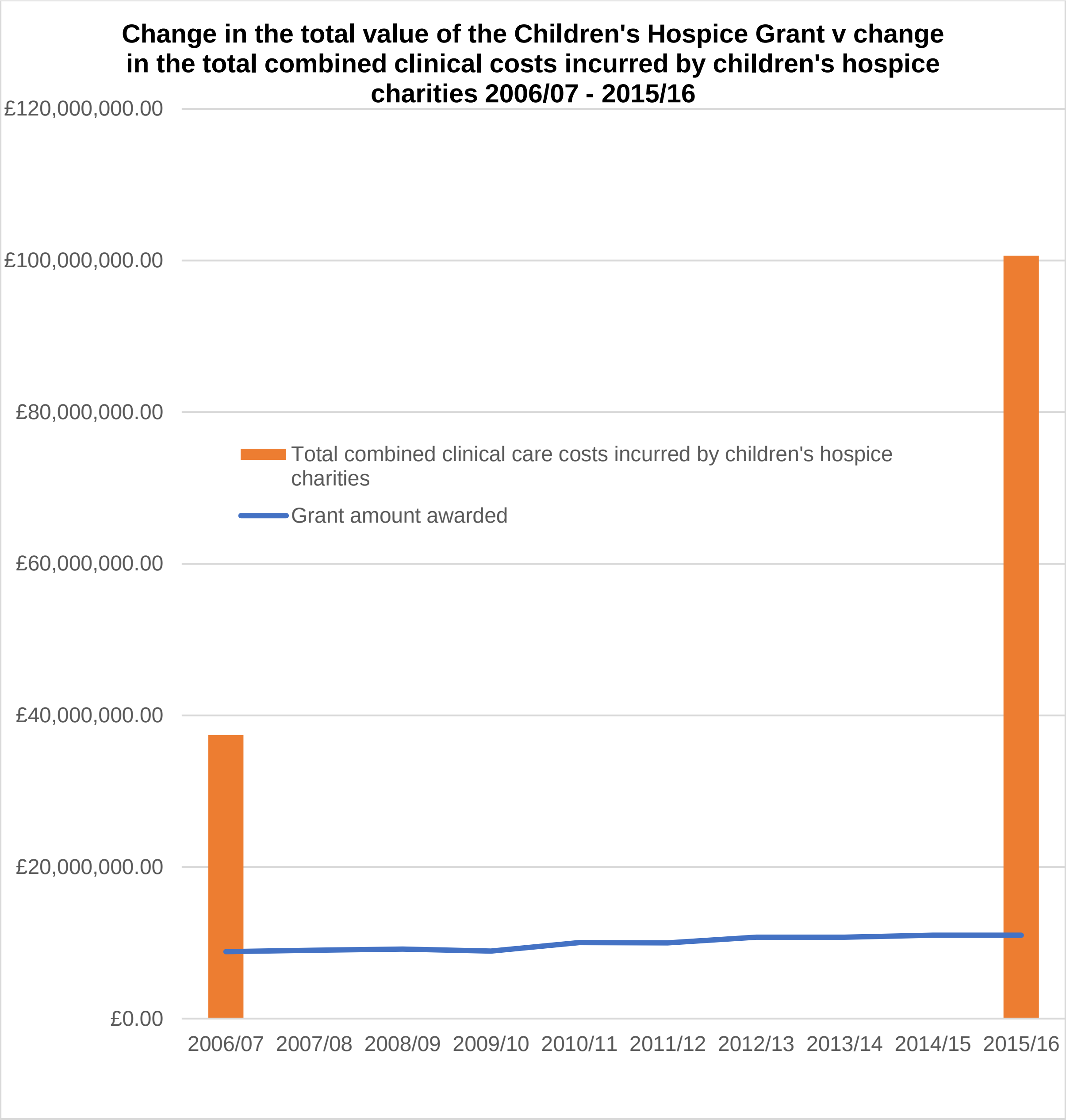
9. The total grant amount has increased incrementally from £8,829,180 in 2006/07 (part of £27million awarded over three years) to £11,000,000 in 2015/16. These increments are set out in the chart and table overleaf**.** Between 2006/07 and 2015/16, the overall increase in the value of the grant was £2,170,820 (25%). While this increase has been welcome, it has not kept pace with the growing cost of providing clinical palliative care incurred by children's hospice charities. In 2006/07, the grant contributed an average of 14% towards the cost of providing clinical care in children's hospices. In 2015/16, when it had risen to £11,000,000, it contributed an average of just 8%.

10. As the chart overleaf shows, among the 31 (86%) of children's hospice charities who provided data about their clinical care costs in 2015/16, the total combined clinical care costs was £100,625,088. This is an average of £3,759,260.15 per charity. Among the 25 (81%) of the 31 children's hospice charities who were providing care in 2006/07, the total combined clinical care costs was £37,423,170. This was an average of £2,086,485.26 per charity. Overall, average combined clinical care costs across inpatient, community and home settings had increased by 80% (£1,672,774.89) since 2006/07.

11. 31 (86%) of children's hospice charities told us that they provided clinical palliative care to 8,735 children in 2015/16 (6,203 in-patient and 2,532 at home and in the community). This was an average of 323 children per children's hospice charity. 21 (68%) of the 31 children's hospice charities who were providing care in 2006/07 told us that they provided clinical palliative care to 3,679 children in 2006/07 (2,609 in-patient and 1,070 at home and in the community). This was an average of 252 children per children's hospice. The average number of children supported by children's hospice charities had therefore increased by 28% between 2006/07 and 2015/16

12. The increase in the grant has therefore not kept pace with the growing number of children and young people which the children's hospice sector has cared for during this same period. In 2006/07, the grant contributed an average of £1,129 per child cared for by a children's hospice charity. In 2015/16, that had fallen to £947 per child. This was a fall of £182.65 (16%) per child.

13. Children's hospices make a crucial contribution to local health economies. Our consultation has found, for example, that 92% of children's hospice charities provided end of life care to children and young people in 2015/16. 89% provided care which helped children manage their complex symptoms and 75% provided step down care. Without children's hospices, this clinical care would otherwise have to be provided and paid for in its entirety by the NHS.



Year	Grant amount awarded	Total combined clinical care costs incurred by children's hospice charities
2006/07	£8,829,180.00	£37,423,170.00
2007/08	£9,000,000.00	
2008/09	£9,150,000.00	
2009/10	£8,918,924.00	
2010/11	£10,009,919.00	
2011/12	£9,999,999.00	
2012/13	£10,720,996.00	
2013/14	£10,720,996.00	
2014/15	£11,000,000.00	
2015/16	£11,000,000.00	£100,625,088.00

What Together for Short Lives recommends

14. We consider it pressing and urgent that the overall amount of funding available through the children's hospice grant reflects the increase in demand, costs and complexity of care needed by children and young people with life-limiting and life-threatening conditions. We recommend that the grant is increased in value to £25million per year. We base this on a 14% contribution to the current cost of the clinical care provided by children's hospices, which is equal to the contribution originally made by the Department of Health when the grant was first awarded in 2006/07. The uplift also recognises any additional costs in developing reporting mechanisms and new services to meet growing demand.

How the grant is allocated

What children's hospice charities have told us

15. A number of respondents challenged whether a compelling case has been made to change the current formula. The consultation shows a lack of consensus amongst those surveyed on a proposed new formula for allocating the children's hospice grant. Many cite the complexity of palliative care needed by children with life-limiting and life-threatening conditions as being a key factor that is not easily reflected in any one option, nor the holistic nature of children's palliative care. There is a small percentage in favour of using charitable costs - this largely relates to simplicity and the fact that these figures are auditable in the organisations' accounts. However, there is also strong and sufficient concern about using this approach in isolation, whether it rewards cost-effectiveness and whether it disadvantages hospices with multiple sites.

16. Some children's hospices have questioned whether moving to an allocation model based on per-patient activity will risk their ability to claim the hospice VAT relief scheme introduced in April 2015. We ask that NHS England provides clarity on the likelihood of this risk materialising, and if it will increase the grant value to mitigate this.

17. Another key challenge is the fact that there is no clear model shared by children's hospices on how children's palliative care is delivered or measured. For example, a number of hospices are moving away from traditional models of activity such as bed occupancy and moving into community-based. Some children's hospice charities are entirely community-based.

18. Children's hospice charities believe that an uplift in grant could be a really important opportunity to stimulate and support ongoing work to achieve agreement around outcomes and models of best practice which could bring about greater efficiencies. This could be work undertaken ahead of the broader strategic review of children's hospice grant funding which NHS England has indicated will take place in 2019/20.

What Together for Short Lives recommends

19. Given that NHS England has indicated that there will be a strategic review of children's hospice grant funding, we recommend that the existing formula remains alongside an increase in the overall funding commitment. This will ensure that services are maintained and a cliff edge of care that any cut that will cause is avoided. The uplift in the total grant pot which we propose would also help provide stability to the sector, allowing NHS England to use this consultation as an informing stepping stone to the proposed strategic review.

How a transition to any new formula for allocating the grant should be managed

What children's hospice charities have told us

20. Most respondents expressed concern about the transition arrangements to a new formula. Many highlighted that they have already budgeted for 2017/18 and any reduction in income or 'funding shocks' would be extremely disruptive and would therefore impact negatively on service provision through cuts.

21. A small number of respondents did ask that a change to the allocation formula happen immediately. This appears to reflects their concern that they are not being fairly funded under the current arrangement.

What Together for Short Lives recommends

22. While we recommend that the current formula for allocating the grant remains in place until the proposed NHS England funding review in 2019/20, if a change is to be implemented before then we ask that it is phased in from 2018/19. In such a situation, we would call on NHS England to provide a clear and early indication of what a new allocation would mean for each hospice so that they can budget and plan accordingly.

23. We believe that NHS England could address the concerns of those children's hospice charities which do not believe they are being fairly funded by increasing the overall value of the grant pot until the proposed strategic review in 2019/20.

Reporting on spend of Children's Hospice Grant

What children's hospice charities have told us

24. Most respondents understood the need for proportionate accountability on how the grant is spent. However, strong concerns have been raised about NHS England's proposal for charities to report per-patient activity in a way which is consistent with the new children's palliative care currency units since the currency does not fully reflect the children's palliative care services and support provided by children's hospices. There is also strong concern that new reporting requirements will cost money to implement - money that would otherwise be spent on care. Whilst we did not ask for a costing of any new reporting requirements, one children's hospice charity cites that this could cost up to £35k per annum.

25. Children's hospice charities also used the consultation to call on NHS England to scrutinise grant recipients to make sure that they are providing children's palliative care to children and young people with life-limiting and life-threatening conditions in return for funding.

What Together for Short Lives recommends

26. We therefore recommend that further consideration be given to the reporting which children's hospice charities are required to provide in return for the grant. This should be done with a view to implementing it in accordance with the proposed review of the children's hospice grant in 2019/20. We recommend that as part of the funding uplift we propose, funding is allocated by NHS England to help charities develop and implement a new reporting system.

27. We also recommend that consideration of reporting requirement forms part of a wider data scoping exercise for children's palliative care that includes concrete plans to builds Minimum Data Set being established for children, as there is for adults.

28. We also recommend that NHS England are as clear as possible about their criteria for determining which charities are eligible for the grant. We call on NHS England to scrutinise grant recipients to make sure that they are providing children's palliative care to children and young people with life-limiting and life-threatening conditions in return for funding.

Further issue raised: Funding managed clinical networks

What children's hospice charities have told us

29. Children's hospice charities engage in local children's palliative care networks and broadly support NICE's proposal to move towards regional managed clinical children's palliative care networks (MCNs). However, a number have made it clear that they would not accept statutory funding currently allocated to children's hospices through the grant being diverted away to fund MCNs.

What Together for Short Lives recommends

30. For clarity, since it was queried by some respondents, Together for Short Lives is not recommending that the Children Hospice Grant be used to fund the managed clinical children's palliative care networks proposed in the NICE Clinical Guideline 'End of Life Care for Infants, Children and Young People'[1]. Any funding allocated to MCNs by NHS England should be separate to the larger children's hospice grant which we propose.

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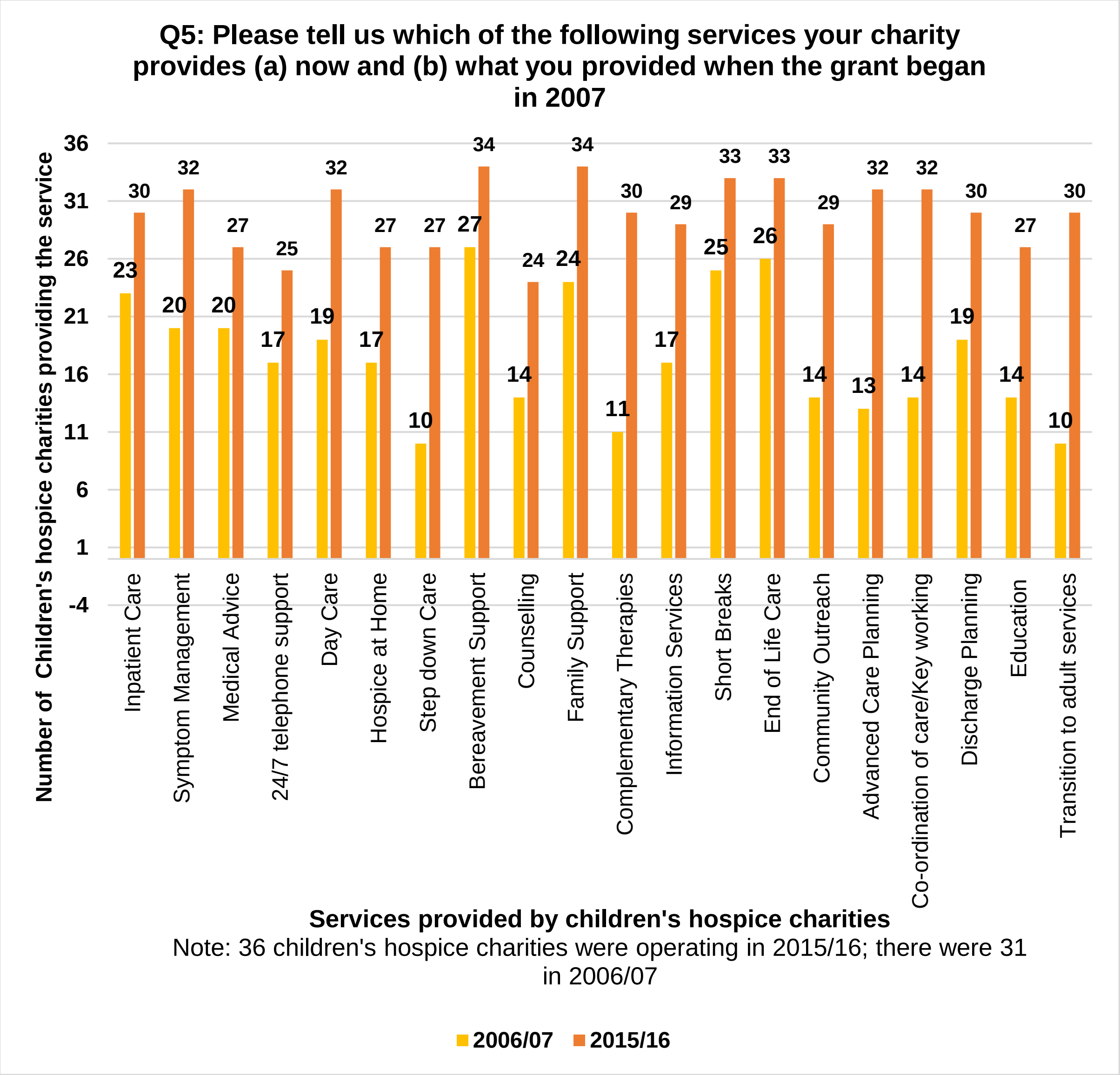
[1] National Institute for Health and Care Excellence (NICE). 2016. End of life care for infants, children and young people with life-limiting conditions: planning and management. Available to download from: https://www.nice.org.uk/guidance/ng61

II. Question by question analysis

Question 5: How services which children’s hospice charities provided have changed between 2006/07 and 2015/16.

31. 34 (94%) of children’s hospice charities told us which services they provided to children and young people with life-limiting and limiting conditions in 2015/16. Of all the services which we asked about, more charities provided them in 2015/16 compared to 2006/07 (see below). The most prevalent services provided by children’s hospice charities in 2015/16 were bereavement support (34 charities), family support (34), end of life care (33) and short breaks (33).

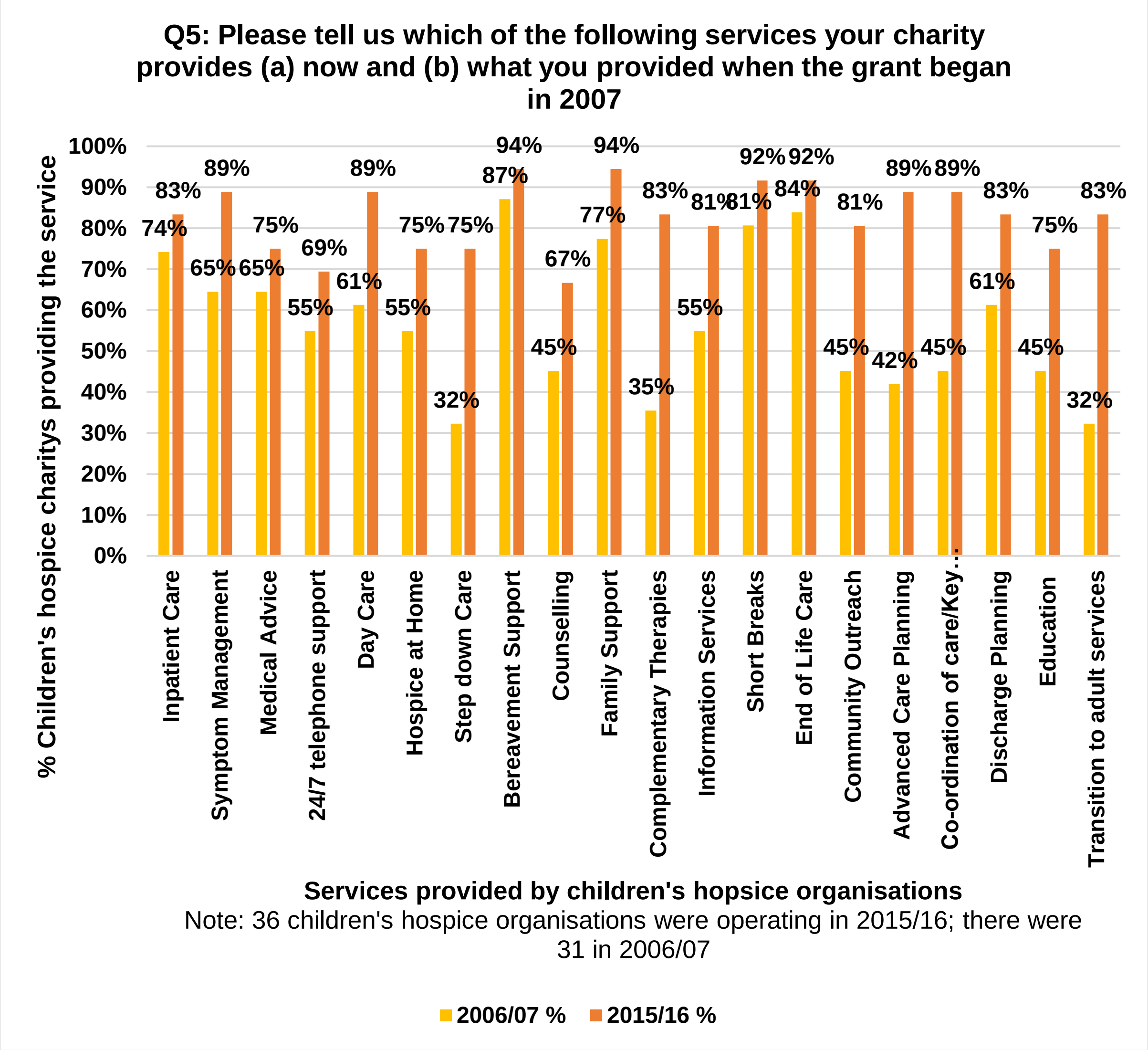

Q5: Please tell us which of the following services your charity provides (a) now and (b) what you provided when the grant began in 2007

Note: 36 children's hospice charities were operating in 2015/16; there were 31 in 2006/07

32. Greater proportions of children’s hospice charities were providing these services in 2015/16 compared to 2006/07, even taking into account the fact that fewer charities were providing care in 2006/07. The greatest increase is in transition services, which were provided by 32% of charities in 2006/07 and 83% of charities in 2015/16.

33. Demonstrating that children’s hospice charities make a crucial contribution to local health economies, our consultation has found, for example, that 92% of children’s hospice

charities provide end of life care to children and young people. 89% provide care which helps children manage their often complex symptoms and 75% provide step down care. Without children's hospices, this clinical care would otherwise have to be provided and paid for in their entirety by the NHS.


Q5: Please tell us which of the following services your charity provides (a) now and (b) what you provided when the grant began in 2007

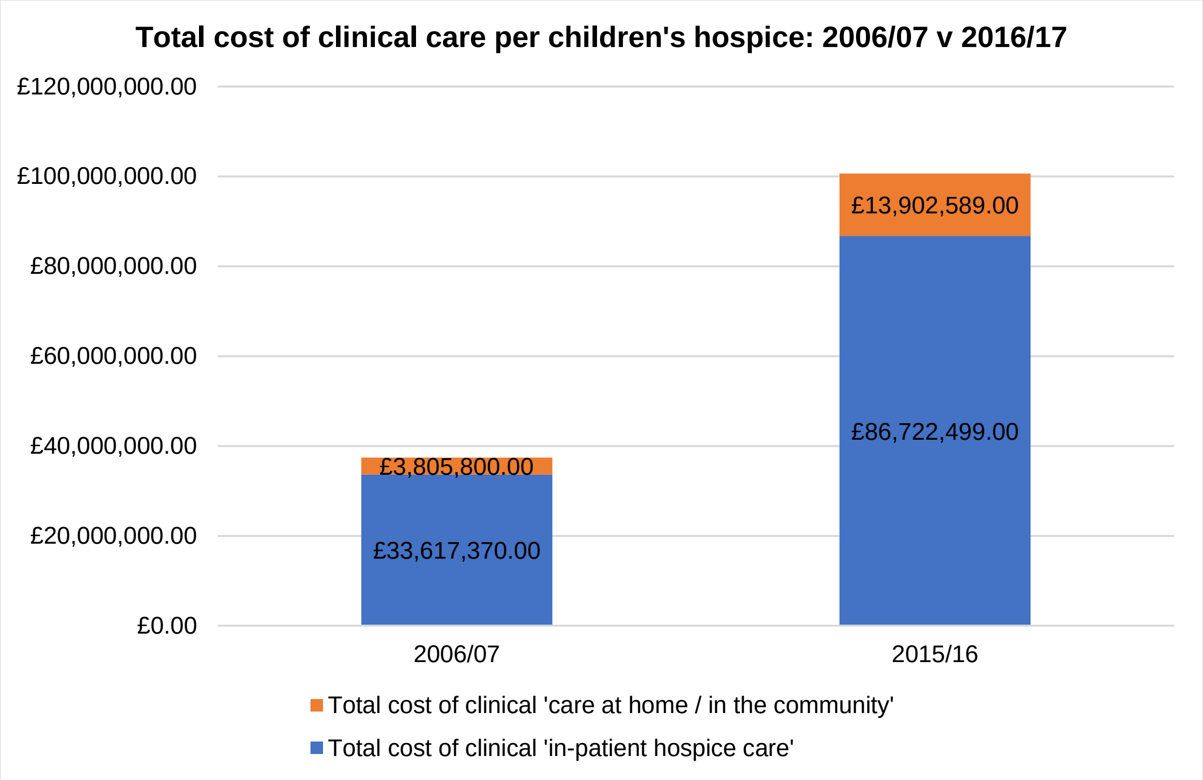
Note: 36 children's hospice organisations were operating in 2015/16; there were 31 in 2006/07

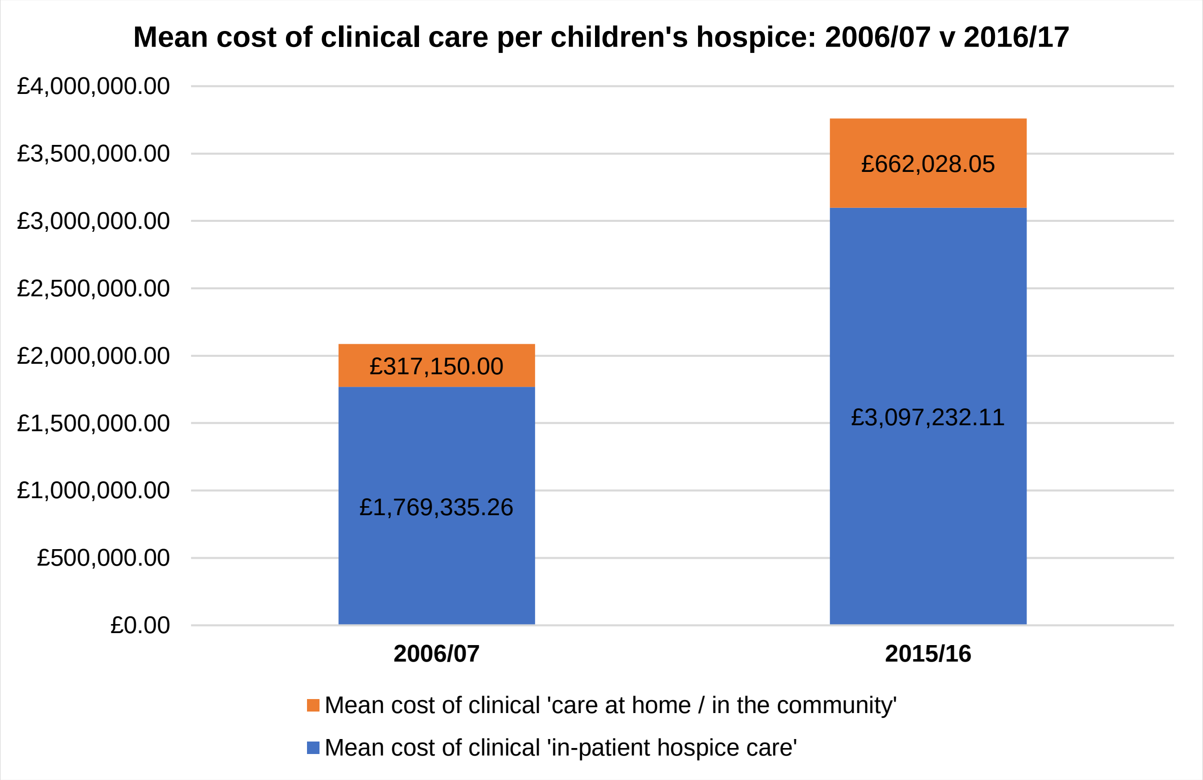
Question 7: How the total charitable clinical costs incurred by children's hospices charities have changed between 2006/07 and 2015/16

34. Among the 31 (86%) of children's hospice charities who provided data about their clinical care costs in 2015/16, their combined total costs were £100,625,088. This was an average of £3,759,260.15 per charity. The cost of inpatient care (£86,722,499) comprised the vast majority of the overall total cost. The cost of care at home and in the community was £13,902,589.

35. Among the 25 (81%) of the 31 children's hospice charities who were providing care in 2006/07, the combined total was £37,423,170. This was an average of £2,086,485.26 per charity. Again, the cost of inpatient care (£33,617,370.00) comprised the vast majority of the overall total cost in 2006/07. The cost of care at home and in the community was £3,805,800.00.

36. Overall, average clinical care costs have increased by 80% (£1,672,774.89) since 2006/07. Total clinical care costs have increased by 169% (£63,201,918.00).

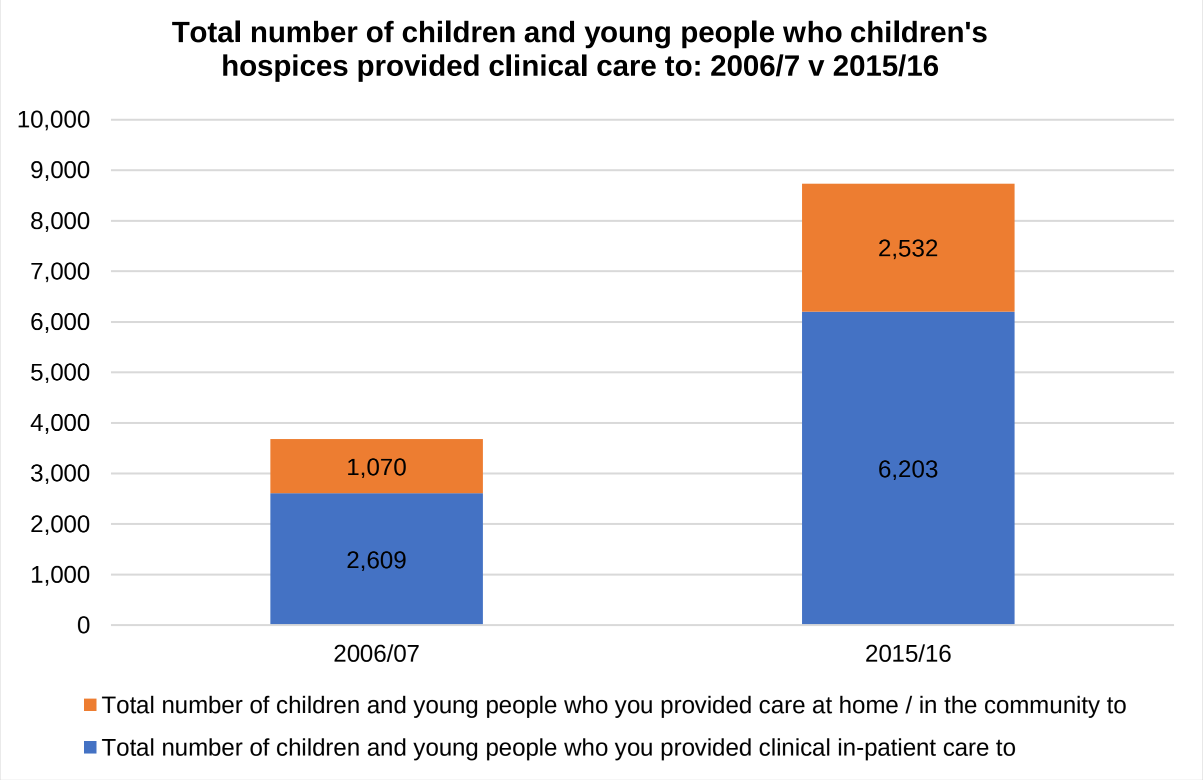

Total cost of clinical care per children's hospice: 2006/07 v 2016/17

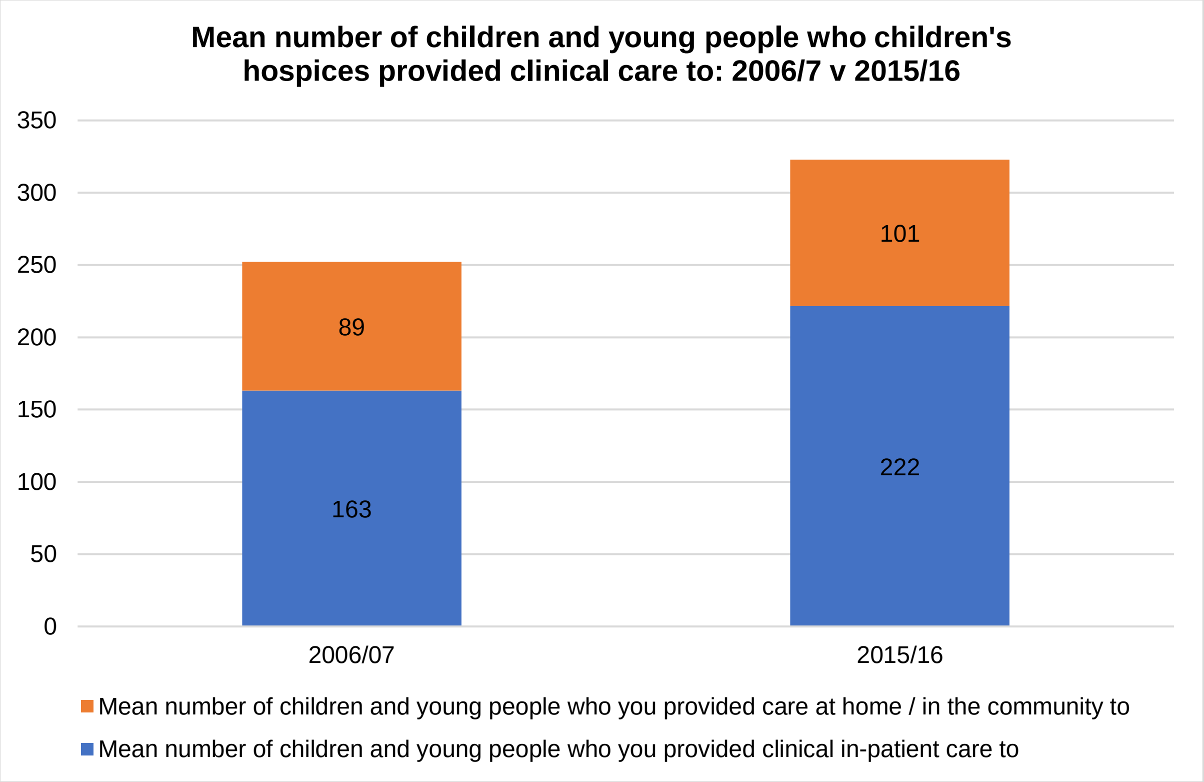

Mean cost of clinical care per children's hospice: 2006/07 v 2016/17

Question 9: How the number of children and young people with life-limiting or life-threatening conditions cared for by children's hospice charities has changed between 2006/07 and 2015/16

37. 31 (86%) of children's hospice charities told us that they provided clinical palliative care to 8,735 children in 2015/16 (6,203 in-patient and 2,532 at home and in the community – see charts below). This was an average of 323 per children's hospice charity. 21 (68%) of the 31 children's hospice charities who were providing care in 2006/07 told us that they provided clinical palliative care to 3,679 children in 2006/07 (2,609 in-patient and 1,070 at home and in the community). This was an average of 252 per children's hospice. The average number of children supported by children's hospice charities has increased by 28% (71 children). The total number of children cared for has increased by 137% from 3,679 to 8,735.

38. These figures should be considered with the caveat that some children will have received both inpatient and home or community-based care during both 2006/07 and 2015/16 and will have been counted twice. Despite this, these figures usefully show the increase in numbers of children accessing care in both settings - and further demonstrate the greater activity undertaken by children's hospice charities during the period 2006/07 to 2015/16.





Question 11: The number of children and young people supported by children's hospice charities in 2015/16 who were ventilator dependent

39. 31 (86%) children's hospice charities answered this question. The mean number of children and young people who were ventilator dependent was 22. The highest number reported was 64 and the lowest number was 0.

Question 12: The number of children and young people supported by children's hospice charities in 2015/16 who required a nurse:patient ratio greater than 1:1

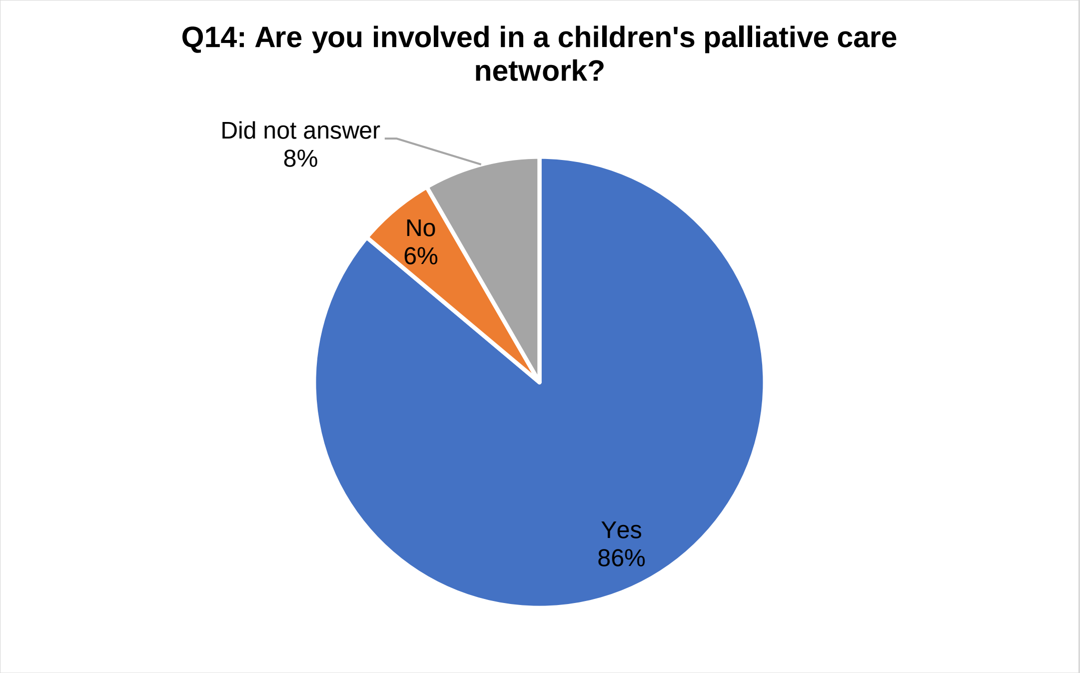
40. 32 (89%) children's hospice charities answered this question. The mean number of children and young people who required a ratio greater than 1:1 was 42. The highest number was 423. The lowest was 0.

Question 13: The average occupancy of the beds available in children's hospices in 2015/16.

41. 30 (83%) children's hospice charities answered this question. The mean average occupancy reported was 73%. The highest reported was 110%. The lowest was 0.

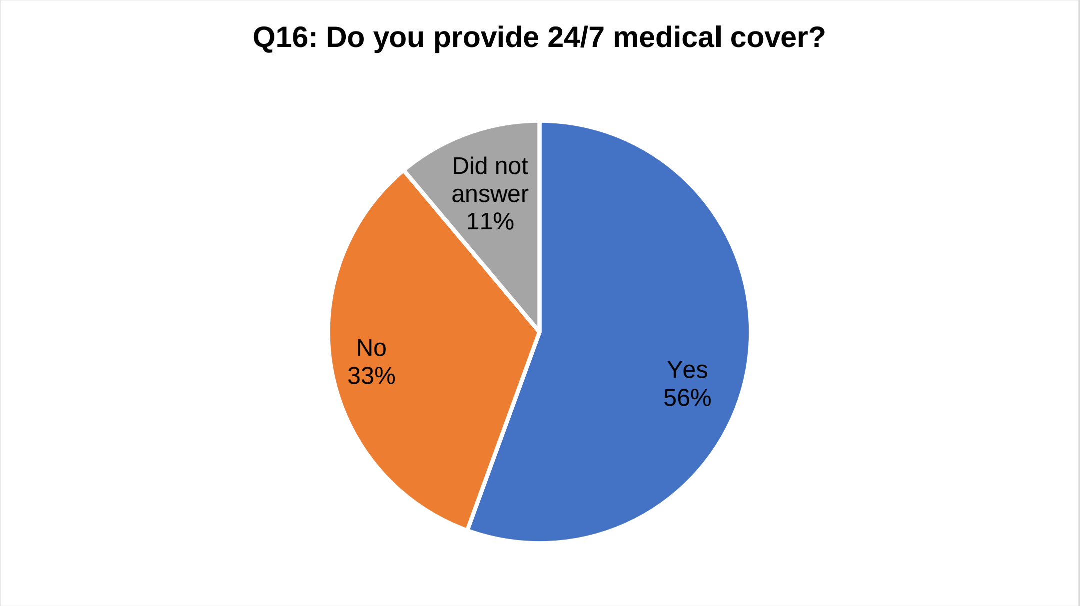
Question 14: The extent to which children's hospice charities are engaged in local children's palliative care networks.

42. 33 (92%) children's hospice charities answered this question. 31 (86%) are part of a local children's palliative care network, and in many cases are members of more than one. Of those charities which are involved in networks, the average is three each. 2 (6%) children's hospice charities are not involved in any networks, while 3 (8%) did not answer this question. See chart below.



Question 16: The extent to which children's hospice charities provide 24/7 medical cover.

32 (89%) children's hospice charities answered this question. 31 (86%) report that they do provide 24/7 medical cover. 2 (6%) do not. 3 (8%) did not answer.



Question 17: The staff employed by children's hospice charities to provide palliative care to children and young people.

43. 24 (66%) of children's hospice charities report that they provide medical care, either directly or via outsourced medical support. 7 (25%) have explicitly told us that they offer level 4 children's palliative care consultant care to children and young people with life-limiting and life-threatening conditions. 8 (22%) have told us that they offer level 3 consultant care. 9 (25%) mention that they offer medical care provided by a GP.

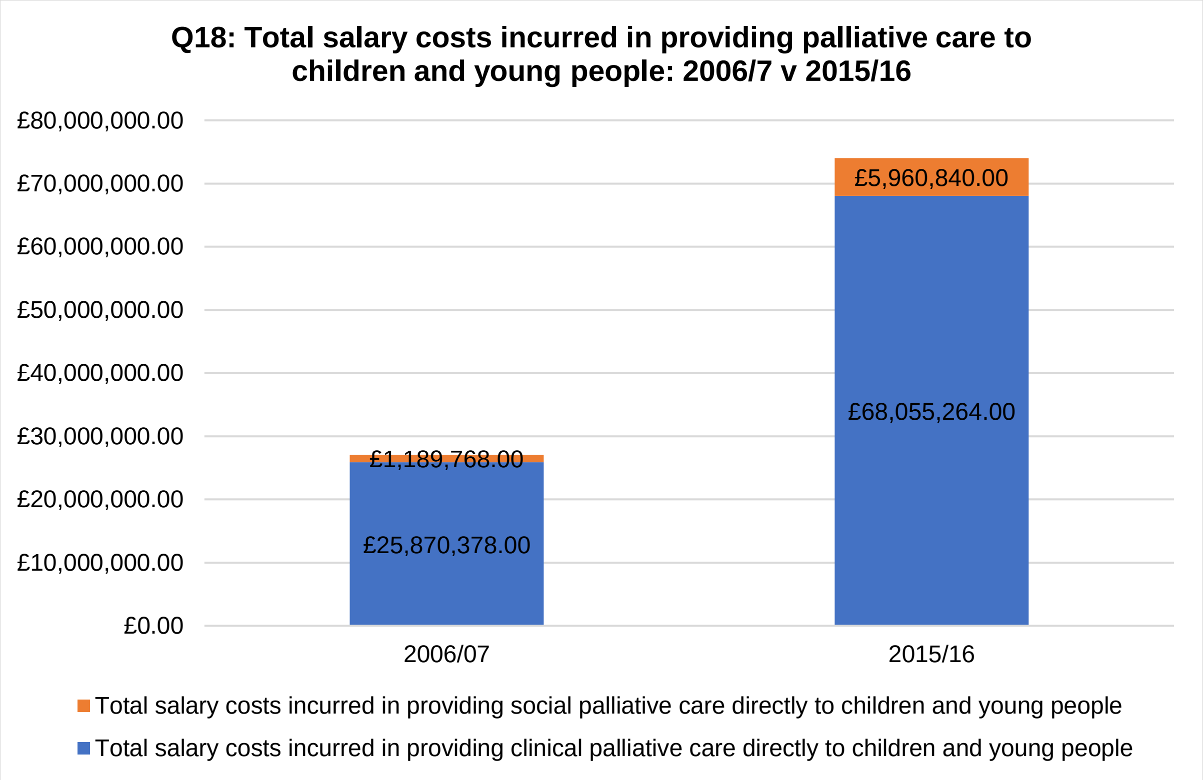
44. 16 (44%) charities have told us that that employ band 8 nurses.16 have also told us that they employ band 7 nurses.

45. 31 (86%) charities report that they employ allied health professionals; 29 (81%) report that they employ social workers. 27 (75%) have described the other types of professional they employ, including play workers, music therapists, counsellors, sibling workers, teachers, chaplains and psychologists.

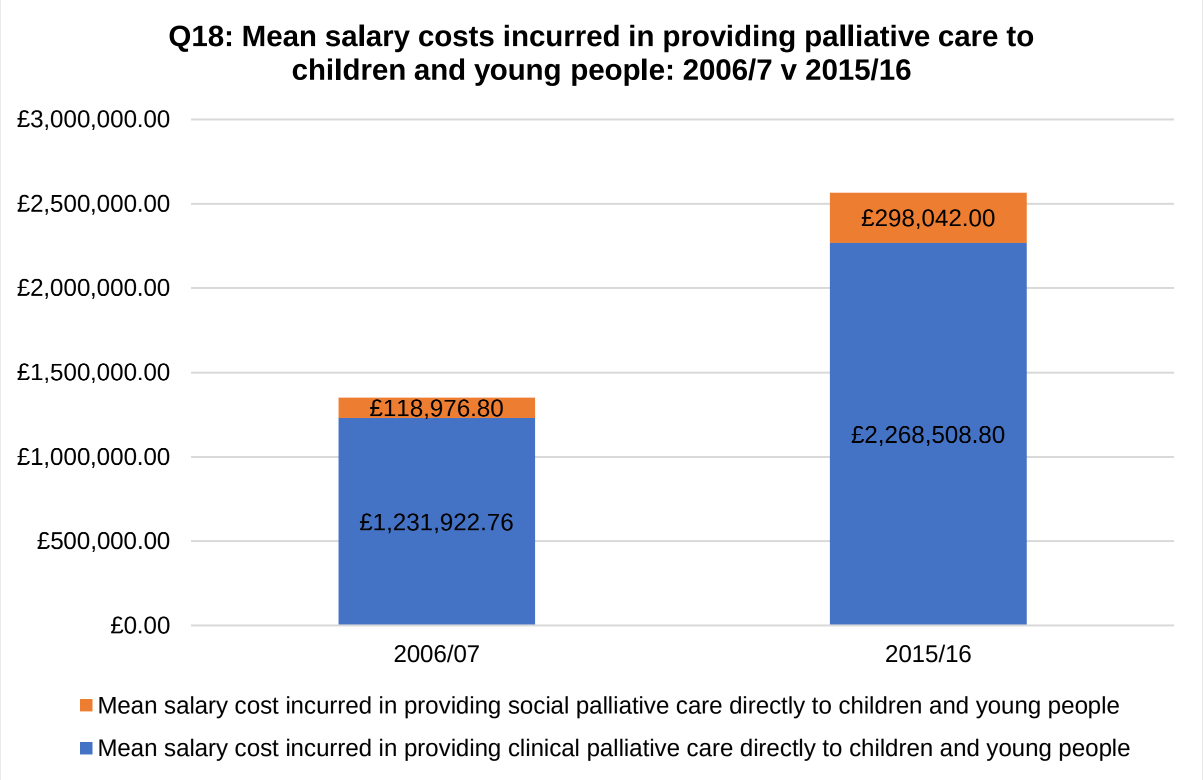
Question 18: How the salary costs incurred by children's hospice charities in providing clinical palliative care have changed between 2006/07 and 2015/16.

46. The total clinical salary cost in 2015/16 incurred by the 30 (83%) of children's hospice charities who provided data was £68,055,264. This was £42,184,886 (163%) greater than the costs reported by the 21 (68%) of charities which provided clinical salary cost figures for 2006/07. The mean clinical salary costs incurred by children's hospice charities rose by £1,036,586.04 (84%) from £1,231,922.76 in 2006/07 to £2,268,508.80 in 2015/16.

47. The total social care salary cost in 2015/16 incurred by the 25 (69%) of children's hospice charities who provided data was £5,960,840. This was £4,771,072 (401%) greater than the costs reported by the 15 (48%) of charities which provided social care salary cost figures for 2006/07. The mean social care salary costs incurred by children's hospice charities rose by £179,065 (151%) from £118,976.80 in 2006/07 to £298,042 in 2015/16.



Q18: Total salary costs incurred in providing palliative care to children and young people: 2006/7 v 2015/16



Questions 20 – 24: Children's hospice charities' preferred formula for allocating the children's hospice grant

48. 33 (92%) answered our question about how the grant should be allocated. As the chart below shows, 9 (25%) charities favoured Formula B, which is based on charitable clinical costs incurred. 3 (8%) support Formula A (based on number of children and young people being cared for by the charity) and 3 (8%) support Formula C (based on clinical salary costs incurred). The most popular option was a combination of the formulas, which was supported by 10 (28%). 8 charities (22%) favoured another method entirely. 3 children's hospice charities did not answer this question.

49. Of those charities which favoured another method entirely, one suggestion was to base funding allocations on direct care costs, excluding support and depreciation costs). Under this model, all hospices would need to demonstrate an efficiency of above 60% to make sure that costs directly relate to activity. Direct care costs would exclude clinical care administrative costs for the purposes of calculating efficiency).

50. A further suggestion includes taking the quality of care provided, as determined by a Care Quality Commission rating, into account in formulating a new means for allocating the grant.

51. Another suggestion is that NHS England consider ringfencing a proportion of the grant for clinical care delivered at home and in the community. This would be determined by the relative percentage England-wide costs for care delivered at home compared to in patient care as reported by hospices. Assuming this ringfence for the inpatient care element of the grant, 100% of the due grant would be paid to the hospice where occupancy was at the average levels reported across all hospices and adjusted up or down proportionately where occupancy was above or below this figure. So if average occupancy was 75%, a hospice reporting 70% would only receive 93% of the grant and a hospice reporting 80% would receive 107%.

52. A number of children’s hospice charities challenged whether a compelling case has been made to change the current formula. The consultation shows a lack of consensus amongst those surveyed on a proposed new formula for allocating the children’s hospice grant. Many cite the complexity care as being a key factor that is not easily reflected in any one option, nor the holistic nature of children’s palliative care.

53. There is a small percentage in favour of using charitable costs - this largely relates to simplicity and the fact that these figures are auditable in the organisations’ accounts. One children’s hospice charity stated is strongly favoured this proposal because:

- it is the only one of the three options which is externally verifiable, through each hospice’s statutory Annual Report and Accounts, which are prepared, audited and submitted according to charity accounting rules and publicly available on the Charity Commission website

- the basis for payment is therefore assured by existing legislation and regulation to be correct and like-for-like

- although other measures, or combinations of measures, might in time provide a more nuanced system of fairness, this is the only existing option which guarantees no possibility of ‘gaming’, no possibility of deliberate or accidental mispayment due to incorrect data submissions, and therefore no scope for appeals or investigations into misallocation of NHS funds

- requires no changes in data reporting systems to provide the information which forms the basis of payment and seems appropriate for a temporary arrangement

- more accurately compensates for the amount of activity undertaken, as charitable expenditure must be spent on charitable care for children, and therefore gives an incentive for hospices to maximise the care they provide

- in terms of efficiency, it should be remembered that the grant only contributes about 10% of hospice funding

- recognises the true role of the grant in the funding profile of hospices: as a contribution to the provision of clinical care provided by predominantly charitably-funded organisations

- is an incentive to increase charitable fundraising and other forms of income generation, in order to provide greater levels of care and assure organisational sustainability, and to maximise value for money and impact in spending (i.e. to improve efficiency)

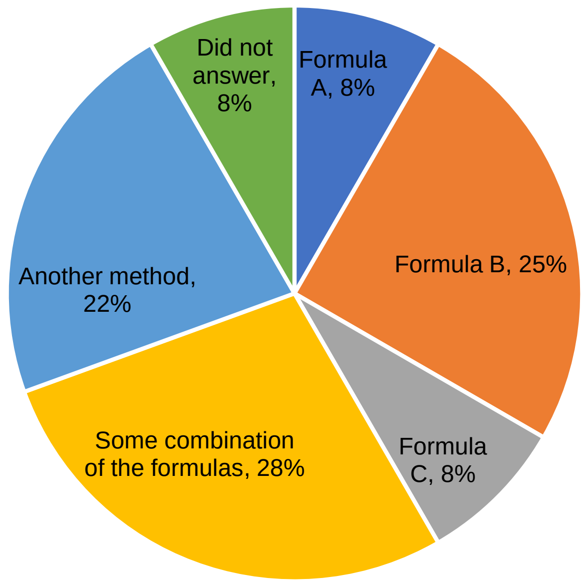
- support and encourage individualised care for those with the greatest and most complex health needs, which is of increasing importance due to the rising numbers of children with increasingly complex health needs

- for a proportion of the total cost, this funding would support the provision of specialised palliative care, supporting children’s hospices in continuing to develop skills in caring for those with complex health needs

- recognises the expenditure required to provide an in-patient facility which gives children and young people options and choice about their place of care and death.

54. However, there is strong and sufficient concern about using this approach in isolation and how it rewards cost-effectiveness and whether it disadvantages hospices with multiple sites; the flaws with Formula B are summed up by one response: “While this method might be fairer than just basing the allocation on numbers of children and young people helped, the difficulty is that it disadvantages the older hospices that were established (and receiving this funding) before many of the newer entrants to the sector were founded. While our costs have not reduced (and have, of course, continued to increase), the effect of this method is likely to be to substantially reduce our funding which will be allocated instead to hospices which have opened more recently. Whilst we agree that they too need access to sustainable funding, the answer to this is not simply to divert funding from the more established hospices. Consideration also needs to be given to other sources of funding for children's hospices, as it's unlikely that any reduction in our NHS England grant allocation will be met by our already generous donors, and we receive virtually no other funding from the state for our children's work. So reducing our grant will definitely impact directly and immediately on our service users.”

Question 23: Which formula do you prefer?



Q25: Managing the transition to the new grant allocation formula

55. Most respondents expressed concern about the transition arrangements to a new formula. Many highlighted that they have already budgeted for 2017/18 and any reduction in income or ‘funding shocks’ would be extremely disruptive and would therefore impact negatively on service provision through cuts.

56. One children’s hospice charity states that it would prefer NHS England to keep the existing system in place until 2019 to avoid undertaking one review, introducing an amended system and then changing this two years later.

57. Another states “We would recommend and argue for one overall review of the Children's Hospice Grant between now and 2019/20 rather than a change in distribution formula now and another potential change in three years’ time. We also seek, as all other children's hospices do, an overall increase in the grant rather than a redistribution of the current fund. An increase in the overall grant fund is long overdue with children's hospices now providing services to more children than ever before with a greater level of complexity of care required meaning costs have increased. With more competition and increased regulation overseeing the raising of voluntary funds, combined with constantly reducing health and social budgets at local level, children's hospices are finding it increasingly difficult to generate the income required to meet the growing needs of children with life limiting or life-threatening conditions.”

58. Some respondents are keen, however, for the transition to the new formula to take place immediately. One young hospice charity claims that it has not benefitted from NHS funding proportionately with its year on year growth. It complains that despite the stasis in the value of the grant since 2013, its care costs and activity have increased phenomenally. It receives 7% of its current care costs from the grant.

Q26: Strengthening the annual reporting requirements of the grant

59. Most respondents understood the need for proportionate accountability on how the grant is spent. However, strong concerns have been raised about the proposal to report against the palliative care currency since the currency does not fully reflect the children’s palliative care services and support provided by children’s hospices.

60. There is also strong concern that new reporting requirements will cost money to implement – money that would otherwise be spent on care.

61. A further concern relates to whether moving to an allocation model based on per-patient activity will risk their ability to claim the hospice VAT relief scheme introduced in April 2015. We ask that NHS England provides clarity on the likelihood of this risk materialising. If it did, this would prove extremely expensive to the children's hospice sector in the loss of recoverable VAT on care costs.

Annex A: The allocation formulas suggested to children’s hospice charities

Formula A: According to the number of children and young people which a children’s hospice actively provided a service for in the last 12 months. Every children’s hospice service applying for the grant would submit the number of children and young people which it provided clinical care for, enabling NHS England to calculate the total number of children and young people receiving hospice care in England. The total grant allocation would be divided by the number of children; this would calculate an amount per child which NHS England would be willing to offer. Hospices would be allocated grant funding based on the number of children and young people they were providing clinical care for at that time. By omitting the charitable costs incurred by children’s hospices from the calculation, we could make sure that any children’s hospices providing more cost-effective care are not unfairly penalised. However, this model fails to take account of differing case mix cared for by children’s hospices; for example, children’s hospices which care for more children with more complex and costly needs would receive no more funding per child than a children’s hospice providing less costly care.

Formula B: According to the charitable costs incurred by each children’s hospice. Every children’s hospice applying for the grant would submit the charitable costs it incurred in providing clinical palliative care directly to children and young people for the previous financial year. This would enable NHS England to calculate the total cost across England and the percentage contributed by each children’s hospice to this total. Hospices would be allocated a percentage of the total grant funding equal to the percentage their charitable costs represent compared to the England-wide total. This model takes account of differing case mix cared for by children’s hospices; for example, a children’s hospice which cares for more children with more complex and costly needs will have higher charitable costs and will receive more funding compared to a children’s hospice providing less costly care. However, children’s hospices providing less cost-effective care (and therefore incurring higher care costs than they could otherwise do) could be unfairly rewarded.

Formula C: According to the salary cost. Every children’s hospice applying for the grant would submit the total salary cost it incurred in providing clinical palliative care directly to children and young people for the previous financial year. This would enable NHS England to calculate the total cost across England - and the percentage contributed by each children’s hospice to this total. Hospices would be allocated a percentage of the total grant funding equal to the percentage their salary costs represent compared to the England-wide total. This model takes account of differing mix of staff employed by children’s hospices; for example, a children’s hospice which employs clinical and nursing staff working at a higher level is likely to have higher salary costs and will receive more funding compared to a children’s hospice employing staff at a lower level. However, salary costs incurred is not necessarily an indicator of a more complex or costly caseload of children and young people, which could lead to some children's hospices potentially being unfairly rewarded. Please share your comments on this proposal.

Annex B: The broader context of children's palliative care statutory funding in England

The following provides important context and commentary on the current statutory funding landscape for children's hospice charities in England:

1. In 2011, a government-commissioned review of funding arrangements for palliative care found that the lack of a clearly defined funding model has led to a wide variation in the level of state funding provided to services, including children's hospices[2]. The only income that children's hospices receive which is committed to by NHS England is the annual £11 million grant, which is split between 36 children's hospice charities. The grant is therefore vital in helping sustain lifeline children's hospice services.

2. The number of children and young people with life-limiting and life-threatening conditions is increasing rapidly. For example, a 2015 report showed a 50% increase over a ten-year period in the number of children and young people with life-limiting conditions in Scotland.[3] This is a dramatic rise; if replicated across the UK then the number of children and young people with life-limiting conditions is very likely to be much greater than the current estimate of 49,000. We believe the value of the overall grant needs to reflect this increase.

3. Together for Short Lives' survey of voluntary sector children's palliative care providers shows that their average charitable expenditure increased by 9.7% in real terms between 2014/15 and 2015/16.[4] This increased spend reflects the growing complexity and demand for children's palliative care.

4. As the children's hospice grant remains static at £11million and children's hospices face increasing costs to support children with life-limiting conditions, the grant is gradually diminishing as a proportion of children's hospices' charitable expenditure.

5. Together for Short Lives' survey of voluntary sector children's palliative care providers shows that the state's overall contribution to the cost of providing children's palliative care in the voluntary sector fell. It was 22% in 2015/16 compared to 23% in 2014/15 and 27% in 2013/14.

6. The wider contribution that children's palliative care charities can expect towards the cost of providing children's palliative care from statutory sources increasingly reflects a postcode lottery. When taking the NHS children's hospice grant and funding from CCGs and local authorities into account, the standard deviation in local authorities' contributions 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. The maximum contribution received by a children's palliative care charity in 2015/16 was over half (53%), while the lowest was 2%.[5]

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[2] Hughes-Hallett T, Craft A and Davies C (2011). Palliative care funding review - creating a fair and transparent funding system; the final report of the palliative care funding review. Available to download from: http://bit.ly/XQBIE7.

[3] Fraser et al. (2015). Children in Scotland requiring Palliative Care: identifying needs and numbers. Available to download from: http://bit.ly/1Krn2EU.

[4] Together for Short Lives (2016). On the brink: a crisis in children's palliative care funding in England. Available to download from: http://bit.ly/2f7HowK.

[5] Ibid.

7. Significantly, over half (59%) of children's palliative care charities would be forced to reduce their services if the children's hospice grant was no longer available.[6] 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%).

8. If children's hospices did not exist, then the cost of care for these children would fall directly to the NHS with additional costs relating to 24/7 support and care and bed use.

9. And yet there is good evidence that investment in children's palliative care saves the NHS money. In December 2016, the National Institute for Health and Care Excellence (NICE) published a new clinical guideline 'End of Life Care For Infants, Children and Young People With Life-Limiting Conditions: Planning and Management'. NICE calculate that by investing £12.7million in implementing the guidance, non-cash savings worth £37.7million would be released back into the NHS in England.

10. We also look to the settlement in Scotland where in October 2016 the Scottish Government announced £30 million of funding over five years to the Children's Hospice Association Scotland. We would like to see a similar long term strategic commitment in England where the needs of children with life limiting and life threatening conditions are as important as those in Scotland.

11. For more information about the statutory funding landscape for children's hospice charities (and other children's palliative care charities) in England, please refer to Together for Short Lives' report 'On the brink: a crisis in children's palliative care funding in England'[7], published in 2016.

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[6] Ibid.

[7] Ibid.