



## 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

June 2016

# Commissioning children's palliative care in England: the results of our freedom of information requests of NHS clinical commissioning groups (CCGs) and local authorities

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## Introduction

This report sets out what Together for Short Lives found as a result of a series of freedom of information (FOIs) requests which the charity made of local authorities and NHS clinical commissioning groups (CCGs) in England during April 2016. The FOIs sought to establish how well these organisations are planning, funding and monitoring (a process known as "commissioning") care for children with life-shortening and life-limiting conditions. From the answers it has received, Together for Short Lives has rated the councils and CCGs by the different aspects of the care needed by children with life-shortening conditions, including end of life care, short breaks and bereavement care. The ratings also take into account whether they commission vital local services for these children, including community children's nurses, children's hospices and specialist medical care. For the first time, the public can see how their local CCGs and councils are performing using [these interactive online maps](#).

The proportion of CCGs and local authorities which responded to each FOI question ranged between 65% and 86%. In total, 187 (88%) CCGs and 144 (93%) local authorities provided some or all of the answers to the questions which we used in calculating the star rating. We would like to work with those CCGs and local authorities which have not yet responded to our FOIs to help them to do so. We will continue to update our tables and maps on a fortnightly basis as we receive more data. The results we publish here take into account the answers we received up until midnight on Friday 3 June 2016.

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## **Executive summary**

- 1. Commissioning in England is the process of planning, agreeing and monitoring services. NHS clinical commissioning groups (CCGs) and local authorities in England have a duty to jointly commission services for disabled children and young people between the ages of 0 and 25.** This should include commissioning palliative care for children and young people with life-shortening conditions.
- 2. Our findings show that the majority of children in England with life-shortening conditions, and their families, are being short changed and ignored.**
- 3. Despite the vital role that local authorities should play commissioning social care for seriously ill children, too few councils are commissioning it:** our survey has shown that only 19% of local authorities say they commission children's palliative care. This means that a staggering 4 out of 5 local authorities are failing to plan and fund care for seriously ill children and young people.
- 4. Overall, children's palliative care commissioning is relatively poor among local authorities:** we have rated 49% of local authorities with our zero or one-star rating.
- 5. Most CCGs are commissioning children's palliative care well:** 65% have achieved our four or five-star rating based on the responses they have made to our FOIs.
- 6. We welcome the fact that a majority (93%) of CCGs say they commission children's palliative care.** However, it is shocking that seriously ill children and young people are being forgotten or ignored by nearly one in 10 CCGs in England.

7. However, **too few CCGs and local authorities and were able to identify exactly how much funding they spent on children and young people with life-shortening conditions.** This is despite us asking them to provide this data in our FOIs.
8. **There are some excellent examples of both CCG and local authorities commissioning the key elements of children's palliative care:** 92% of CCGs commission end of life care for children with life-shortening conditions; over three-quarters (77%) of CCGs commission short breaks.
9. **Whether or not families of seriously ill children have access to round the clock community nursing support depends on where they live:** we are delighted that 94% of CCGs commission community children's nursing (CCN) for children with life-shortening conditions. However, this dropped to 73% when we asked CCGs if they commission a CCN service for children with life-shortening conditions out of hours and at weekends. This means that too many seriously ill children may need to be admitted to hospital if their condition deteriorates rapidly, rather than receive palliative care in the community if that is what they choose.
10. **Local authorities have a legal duty to provide short breaks for disabled children, including children with life-shortening conditions.** Despite this, one in seven (14%) do not commission short breaks for children with life-shortening conditions.
11. **There is a responsibility and accountability vacuum for commissioning children's palliative care; some CCGs and local authorities do not understand what they should be commissioning:** Six CCGs (4%) wrongly told us that NHS England are responsible for directly commissioning children's palliative care. While NHS England should directly commission specialised children's palliative care, including managing complex symptoms and prescribing unlicensed medicines, CCGs and local authorities are responsible for commissioning general children's palliative care. 32% of local authorities said we should ask the local CCG instead when we asked them if they commission children's palliative care, despite the vital role that local authorities should play commissioning short breaks and some equipment and emotional and psychological support services.
12. **Seven CCGs (4%) and two local authorities (2%) have told us that they 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 outcomes<sup>1</sup>."
13. **Too many commissioners misunderstand the difference between commissioning and funding children's palliative care:** many CCGs and local authorities have told us that they think they are commissioning children's palliative care because they are part-funding their local children's hospice. While this investment is very welcome, on its own, it does not mean they are commissioning a holistic service. This should include planning, funding and monitoring other important services such as community children's nursing, community paediatrics, specialist medical input and social care.

## Summary of our recommendations

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<sup>1</sup> VCSE Review. 2016. <http://bit.ly/1XBY5jx>

1. **CCGs and local authorities should implement Together for Short Lives' guide to jointly commissioning palliative care for children and young people aged 0 – 25.**
2. **The government and NHS England should communicate commissioning responsibilities more clearly.**
3. **Government, NHS England, CCGs and local authorities should work with Together for Short Lives to better understand numbers and needs.**
4. **The government and NHS England should hold CCGs and local authorities to account for the way they commission children's palliative care.**
5. **Parliamentarians and the public should press commissioners to do better for children with life-shortening conditions.**

### **What are CCGs and local authorities obliged to do for children with life-shortening conditions?**

CCGs and local authorities have a legal duty to jointly commission services for disabled children under the Children and Families Act 2014. Section three of the SEND Code of Practice<sup>2</sup> sets out in detail what local areas **must** and should do to jointly commission services for children and young people aged 0 – 25 with SEND.

The Short Breaks Regulations<sup>3</sup> set out how local authorities in England **must** provide breaks from caring for carers of disabled children. Breaks should support carers to continue to care for their children at home and to allow them to do so more effectively. The regulations require local authorities to do three things:

1. Ensure that, when providing short breaks, they have regard to the needs of different types of carers - not just those who would be unable to continue to provide care without a break.
2. Provide a range of breaks, as appropriate, during the day, night, at weekends and during the school holidays.
3. To provide parents with a short breaks services statement detailing the range of available breaks and any eligibility criteria attached to them.

Section 2.10 of the 'Short breaks for carers of disabled children: departmental advice for local authorities'<sup>4</sup> states that health services directly provide and commission short breaks for children with complex health needs including children's hospice care and support local authority and voluntary and community sector provision.

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<sup>2</sup> Department for Education. 2014. Special educational needs and disability code of practice: 0 to 25 years. Available to download from: <http://bit.ly/1kOCi5i>

<sup>3</sup> Department for Education. 2011. Short breaks for carers of disabled children: departmental advice for local authorities. Available to download at: <http://bit.ly/1EmRyvM>

<sup>4</sup> Department for Education. 2010. Short breaks for carers of disabled children: departmental advice for local authorities. March 2011 <http://bit.ly/1EmRyvM>

In 2011, an [Independent Palliative Care Funding Review](#)<sup>5</sup> was commissioned by the government. On page 59, the team recommends that:

1. Short breaks which represent planned in-patient and/or community care (for example, to monitor the clinical needs of the patient and to make any necessary adjustments to their care) fall under clinical care as outlined above and should be funded through the palliative care tariff, according to the needs of the child or young person.
2. Short breaks which provide respite for the carers and families of children requiring palliative care should be funded by local authorities and the NHS under their respective legal short breaks duties.

The review report also states that these “duties” refer to the short breaks duty on local authorities and the legal precedence which establishes that the NHS is responsible for short breaks where the ‘scale and type of nursing care’ is such that it is outside that which can be provided by the local authority (*R (T, D and B) v Haringey LBC*).

## **What we have found**

For definitions of the different elements of children’s palliative care and children’s palliative care services which we refer to here, please refer to [Together for Short Lives’ ‘Definitions’ webpage](#)<sup>6</sup> and Together for Short Lives’ *Core Care Pathway for Children with Life-limiting and Life-threatening Conditions*<sup>7</sup>

### ***Are CCGs and local authorities commissioning palliative care for children and young people with life-shortening conditions between the ages of 0 and 25?***

Of the 136 CCGs which have responded to this question, 127 (93%) have answered that are commissioning children’s palliative care. However, of the 130 local authorities which answered the same question, only 24 local authorities (19%) answered that they are commissioning children’s palliative care.

Shockingly, seven (4%) of CCGs and two local authorities (2%) volunteered that they refuse to commission children’s hospices because they are charities - this despite the government and NHS England emphasising the important role of charities generally in providing health and social care services. Six (4%) of CCGs also wrongly say that only NHS England is the commissioning body for all children’s palliative care. While NHS England is responsible for commissioning specialised children’s palliative care<sup>8</sup>, CCGs and local authorities should commission the general elements of children’s palliative care. Specialised children’s palliative care includes services which manage complex symptoms and prescribe unlicensed medicines. It is commissioned directly by NHS England<sup>3</sup>.

32% of local authorities said we should ask the local CCG instead when we asked them if they commission children’s palliative care. This is despite local authorities and CCGs being

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<sup>5</sup> 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: [bit.ly/XQBIE7](http://bit.ly/XQBIE7).

<sup>6</sup> Together for Short Lives. 2016. Definitions. Available to download from: <http://bit.ly/1sx4qko>

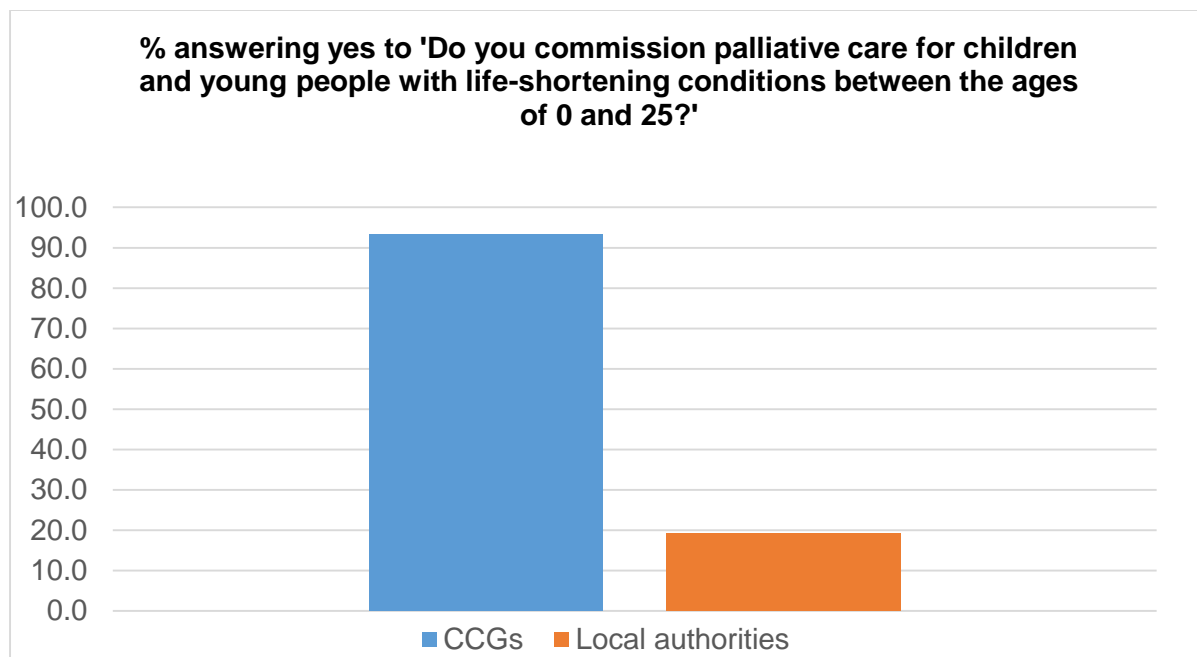
<sup>7</sup> Together for Short Lives. 2016. Core care pathway. Available to download from: <http://bit.ly/1yyeuoT>

<sup>8</sup> NHS England (2013). E03/S/h - 2013/14 NHS standard contract for paediatric medicine: palliative care particulars, schedule 2 – the services, A - service specifications. Available to download from: [bit.ly/11yjtVS](http://bit.ly/11yjtVS).

legally obliged to jointly commission services for children with special educational needs and disabilities (SEND).

### ***A note on CCG and local authority funding for children's palliative care***

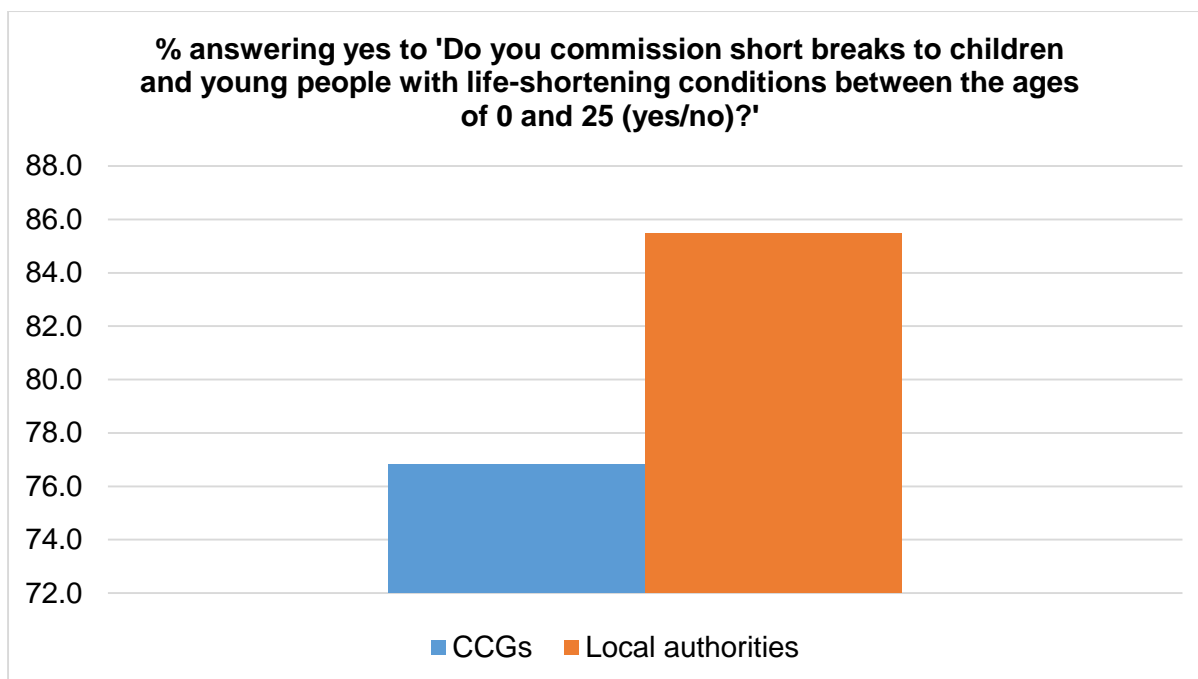
It was disappointing that, through these requests, we were unable to accurately understand how much local authorities and CCGs spend on children with life-shortening conditions across the country. Although we asked each CCG and local authority how much they spend on short breaks, step-down care, end of life care and transition, very few were able to determine this spending. You can view those who were able to do so in the data tables published alongside this report.



### ***Are CCGs and local authorities commissioning short breaks for children and young people with life-shortening conditions?***

Of the 151 CCGs which responded to this question, 116 (77%) state that are commissioning short breaks for children and young people with life-shortening conditions. Encouragingly, while a number have volunteered they do so jointly with their local authority, a number have also referred to us their local authority on the basis that they believe that it is not their responsibility.

Of the 124 local authorities which responded to this question, 106 (86%) state that they are commissioning short breaks for children and young people with life-shortening conditions. While we are encouraged by this high proportion, this still means that 14% (one in seven) of local authorities are failing to do so - potentially contravening their legal duty to provide short breaks for disabled children.



***Are CCGs commissioning step-down care for children and young people with life-shortening conditions?***

Step-down care is a service for children who are medically and clinically stable and fit for discharge from hospital but unable to go home because:

- there are short-term, medical and clinical needs and an intermediary solution is required; or
- there are longer term conditions that need to be available at home that are not yet ready, for example a continuing care package, specialist training or appropriate housing adaptations are required.

138 CCGs answered this question; 94 (68%) of these told us that they do commission step-down care for children and young people with life-shortening conditions.

***Are CCGs commissioning end of life care for children and young people with life-shortening conditions?***

145 CCGs answered this question; 133 (92%) of these told us that they do commission end of life care for children and young people with life-shortening conditions.

***Are CCGs commissioning transitions between children’s and adult services?***

Of the 142 CCGs which answered this question, 118 (83%) stated that they do commission transitions between children’s and adult services for breaks for children and young people with life-shortening conditions.

***Are CCGs commissioning specialist medical input?***

178 CCGs answered this question; of these, 128 (72%) are commissioning specialist medical input for children and young people with life-shortening conditions.

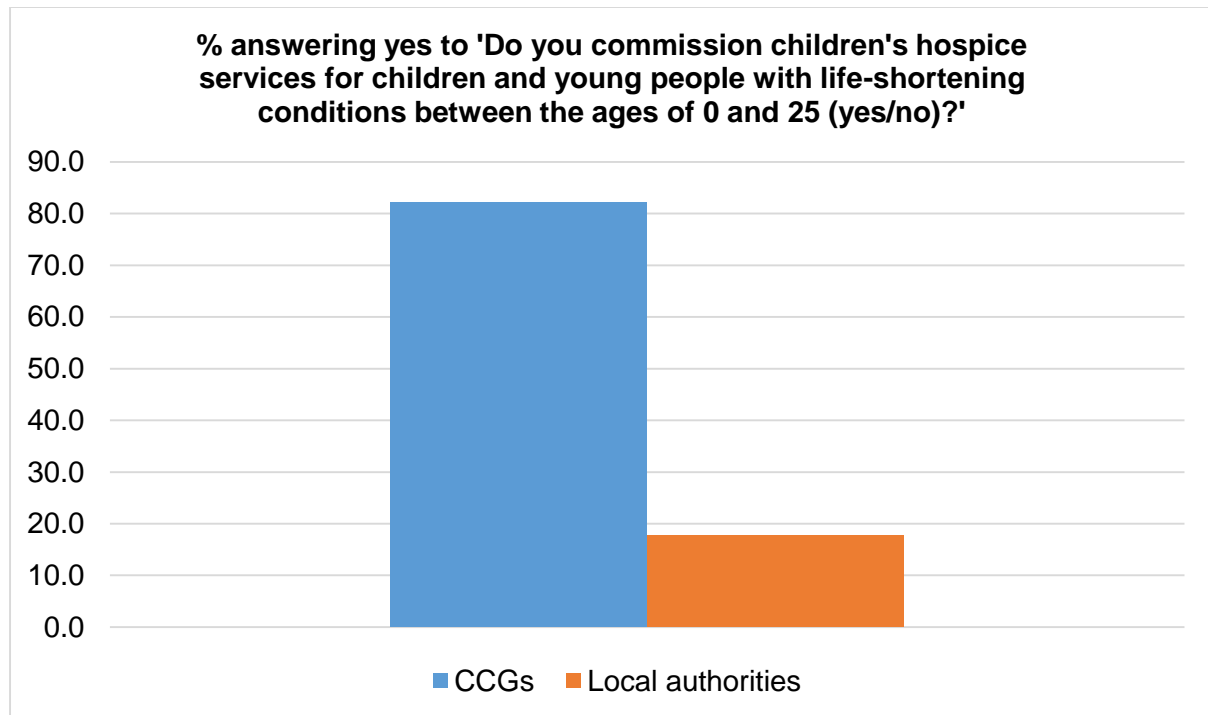


60% of 132 CCGs who answered are commissioning this care out of ours and at weekends.

**Are CCGs commissioning community children's nursing?**

Of the 179 CCGs which answered this question, 169 (94%) said that they commission community children's nursing for children and young people with life-shortening conditions. 119 CCGs (73%) are commissioning this out of hours and at the weekend - a question answered by 163 CCGs.

**Are CCGs and local authorities commissioning children's hospice services out of hours and at weekends?**



179 CCGs have answered this question: of those which have, 147 (82%) state that they commission children's hospice services. A similar proportion (82%) of CCGs say that they commission these services out of hours and at weekends; 164 of CCGs answered this latter question.

129 local authorities answered the question 'Do you commission children's hospice services for children and young people with life-shortening conditions between the ages of 0 and 25?' Disappointingly, of these, only 23 (18%) answered yes. 128 have answered our question on whether they commission children's hospices out of hours and at weekends. 18% of local authorities say that they do.

**Are CCGs commissioning community paediatrics out of hours and at weekends?**

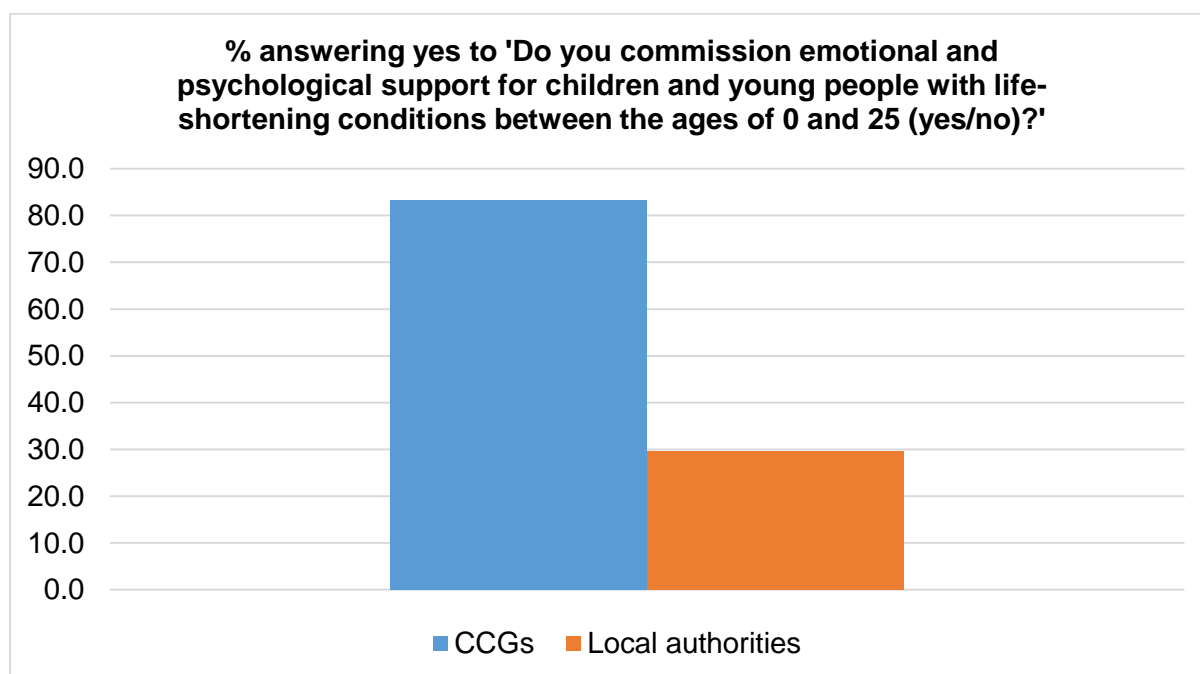
179 CCGs answered our question 'Do you commission community paediatrics for children and young people with life-shortening conditions between the ages of 0 and 25?' Of those that did, 166 (93%) said that they do commission these services.

However, only 58 (37%) of CCGs say that they commission community paediatrics for children and young people with life-shortening conditions out of hours and at weekend. 158 CCGs answered this question.

**Are CCGs and local authorities commissioning emotional and psychological support - including bereavement care?**

179 answered our question 'Do you commission emotional and psychological support - including bereavement care - for children and young people with life-shortening conditions between the ages of 0 and 25?'. Of those that did, 149 (83%) answered 'yes'. This figure falls to 92 (61%) when CCGs were asked if they commission these services out of hours and at weekends. 152 CCGs answered this second question.

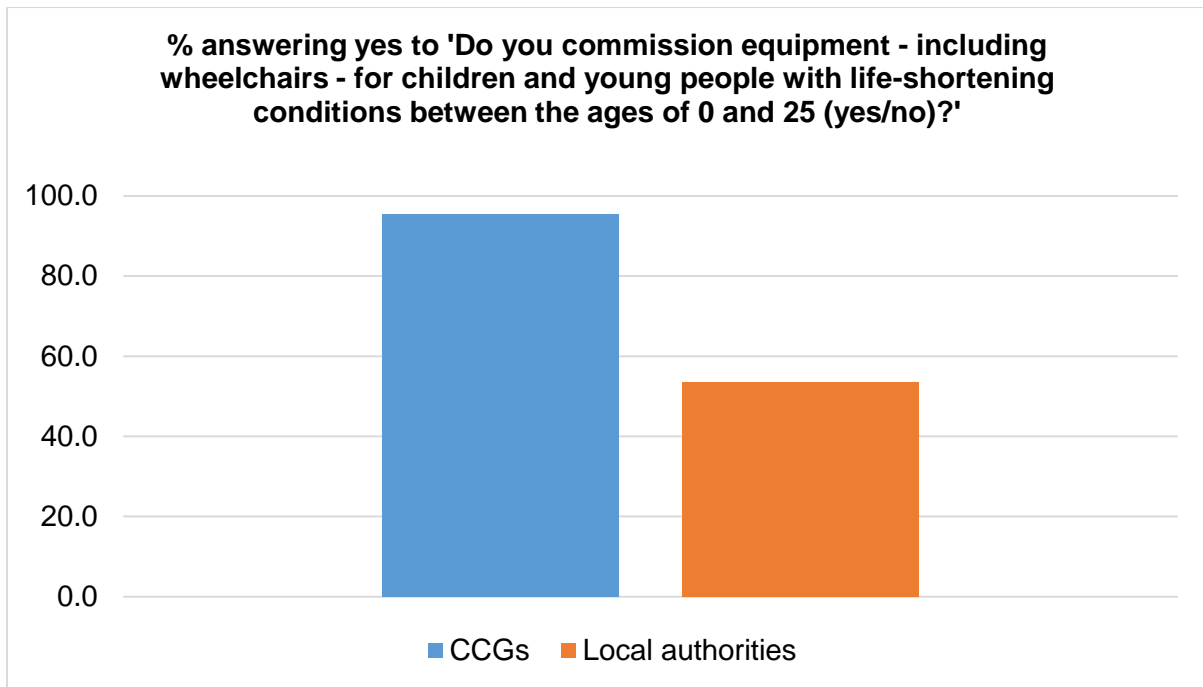
The proportion of local authorities which commission these services is much lower. Of the 128 which answered this question, only 38 (30%) local authorities say that they commission emotional and psychological support - including bereavement care - for children and young people with life-shortening conditions between the ages of 0 and 25. This figure drops even further to 18 local authorities (16%) which commission these services out of hours and at weekends. 114 answered this second question.



**Are CCGs commissioning equipment - including wheelchairs - out of hours and at weekends?**

168 (96%) of the 176 CCGs which answered this question state that they are commissioning equipment for children and young people with life-shortening conditions. Only 53 (38%) of 139 CCGs say that they are commissioning these services out of hours and at weekends.

67 (54%) of the 125 local authorities which answered this question say that they are commissioning these services for children and young people with life-shortening conditions. This drops to 31 (28%) of local authorities who say that they are commissioning this out of hours and at weekends. 112 answered this second question.



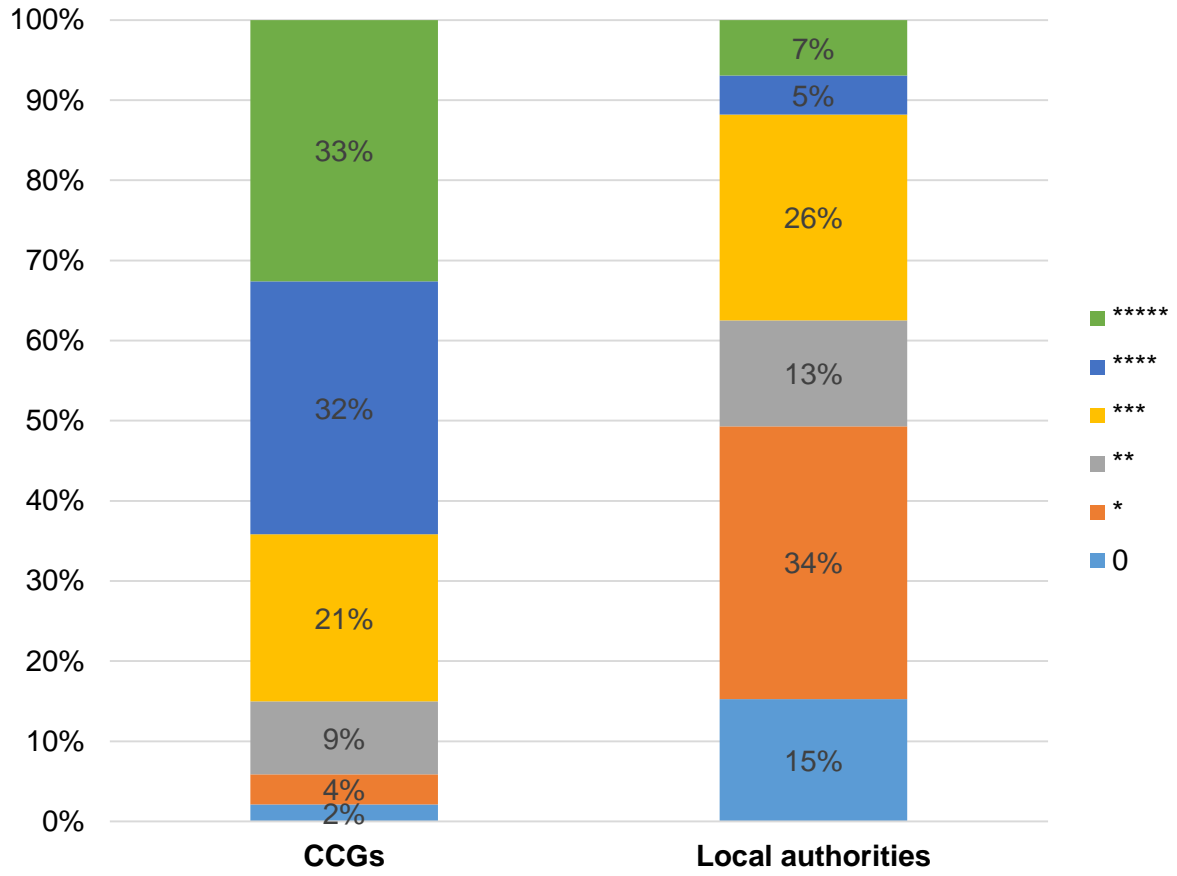
***Together for Short Lives' star ratings***

When considering the way in which our star ratings are distributed across CCGs and local authorities in England, we can see that, disappointingly, nearly half (49%) of local authorities have received Together for Short Lives' zero or one-star rating for children's palliative care. Only 7% achieved the maximum of five stars.

Overall, 65% of CCGs received a four or five-star rating. Just 2% received our zero or one-star rating.

You can read how we calculated our star rating in [Appendix One](#).

**Distribution of Together for Short Lives' star ratings across CCGs and local authorities**



## What do we want to happen as a result of our findings?

In publishing the results of our survey, we hope to take a constructive and collaborative approach with government, NHS England, CCGs and local authorities to:

- identify local gaps in commissioning
- highlight and celebrate those areas which are planning effectively and funding children's palliative care equitably and sustainably - and publicise how they are doing it
- make the public aware of the steps which we would like CCGs and councils to take to jointly commission and fund children's palliative care - and encourage the public to write to their CCGs and local authorities
- encourage the public to write to their MPs to ask them to press their CCGs and local authorities to jointly commission children's palliative care
- make sure that commissioners are aware of the help that Together for Short Lives can offer them in making sure that seriously ill children can access the palliative care they need.

We would like to act as a partner with government and other agencies to help make sure the following actions are taken as a result of our findings:

1. **Implement our guide to commissioning children's palliative care:** 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.
2. **Communicate commissioning responsibilities more clearly:** 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.
3. **Better understand numbers and needs:** We would like the government and NHS England to work with CCGs and local authorities to make sure that the number and needs of children and young people with life-shortening conditions are more accurately monitored. This will mean that we can:
  - a. all understand the true demand for children's palliative care
  - b. identify the gaps in care for children with life-shortening conditions
  - c. make sure that care is planned and funded more effectively to meet the needs of children with life-shortening conditions.
4. **Hold commissioners to account:** We would like the government and NHS England to hold CCGs and local authorities to account for the way in which they are commissioning children's palliative care, through the NHS outcomes framework, clinical commissioning group outcomes indicator set (CCGOIS) and other frameworks. This should include holding local authorities to account to increase funding for short breaks for disabled children - 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.

5. **Press commissioners to do better:** We would like the public and Parliamentarians to find out how their local CCGs and local authorities are performing from our map and data tables. We would like them to ask their CCGs and local authorities what steps they will take to address the gaps in children's palliative care commissioning highlighted by our survey.

## Appendix one: our methodology

The figures we quote in our analysis are calculated from the responses which Together for Short Lives has received to a series of freedom of information (FOIs) made of all 209 CCGs and all 152 upper-tier local authorities between 4 April and 12 April 2016. You can view the questions we asked in [Appendix Two](#).

In our analysis, the figures we provide are expressed as percentages of CCGs and local authorities who have answered yes or no to each question. The sample of CCGs and local authorities for each question is slightly different in terms of size and composition, depending on which have answered it so far. We have published the responses to all the questions we have posed to [CCGs here](#) and [local authorities here](#).

*How has Together for Short Lives calculated its star rating system?*

Together for Short Lives has calculated its star rating of CCGs and local authorities based on the number of 'yes' answers which they have given to the questions we asked them. The more 'yes' answers given, the higher their rating:

- 0% of 'yes' answers = 0 stars
- 1 - 20% = one star
- 21% - 40% = two stars
- 41% - 60% = three stars
- 61% - 80% = four stars
- 81% - 100% = five stars

Please note that we have not included the answers to the question 'Do you commission palliative care for children and young people with life-shortening conditions between the ages of 0 and 25' in our rating calculation. This is because it is an overarching question; the questions which we do take into account seek to explore whether CCGs and local authorities are commissioning the different elements which comprise children's palliative care. We separate them because we want to show cases where these organisations are not actually commissioning children's palliative care when they are claiming to do so - and, conversely, if they are actually commissioning children's palliative care when they think they are not. Our results have found that both scenarios are occurring. This could be because some commissioners do not understand what the term 'children's palliative care' means. By publishing the results of our survey, we hope that CCGs and local authorities will better understand what children's palliative care is and what their role in commissioning it is.

**It is for this reason that Together for Short Lives been able to give a star rating to CCGs and local authorities who have told us that they do not commission children's palliative care.**

In total, 187 (88%) CCGs and 144 (93%) local authorities provided some or all of the answers to the questions which we used in calculating the star rating. We would like to continue to work with those CCGs and local authorities who have not yet responded to our FOIs to help them to do so. We will continue to update our tables and maps on a fortnightly basis as we receive more data from them. The results we publish here take into account the answers we received up until midnight on Friday 3 June 2016.

## **Appendix two: Together for Short Lives' freedom of information requests of CCGs and local authorities in England**

### **CCG FOI questions**

1. Do you commission palliative care for children and young people with life-shortening conditions between the ages of 0 and 25? (yes/no)
2. Do you commission any of the following services to provide care out of hours and at weekends?
  - Specialist medical input (e.g. medical consultants with expertise in life-shortening conditions) (yes/no)?
  - Community children's nursing (yes/no)?
  - Children's hospice services (yes/no)?
  - Community paediatrics (yes/no)?
  - Emotional and psychological support - including bereavement care (yes/no)?
  - Equipment - including wheelchairs (yes/no)?
3. Do you commission the following services to children and young people with life-shortening conditions between the ages of 0 and 25 (yes/no)? If yes, please state how much you will spend on this in 2015/16:
  - short breaks
  - step-down care
  - end of life care
  - transitions between children's and adult services.

### **Local authority FOI questions**

4. Do you commission palliative care for children and young people with life-shortening conditions between the ages of 0 and 25? (yes/no)
5. Do you commission any of the following services to provide care out of hours and at weekends?
  - Children's hospice services (yes/no)?
  - Emotional and psychological support - including bereavement care (yes/no)?
  - Equipment - including wheelchairs (yes/no)?
6. Do you commission short breaks to children and young people with life-shortening conditions between the ages of 0 and 25 (yes/no)? If yes, please state how much you will spend on this in 2015/16.



## Appendix three: what is commissioning?

NHS England states<sup>9</sup> that commissioning is the process of planning, agreeing and monitoring services. It is not one action but many, including:

- assessing the health needs of a population
- designing clinically-based patient pathways
- specifying services
- negotiating contracts and procuring services
- continually assessing the quality of services.

It is not simply the act of funding a particular service.

1. Assessing needs
2. Reviewing services and analysing any gaps in provision
3. Managing risk
4. Deciding priorities
5. Strategic options
6. Contracting
7. Provider development
8. Managing the performance of providers



Courtesy of The NHS Information Centre for health and social care. Full diagram available at: [www.nhs.uk/commissioning](http://www.nhs.uk/commissioning)

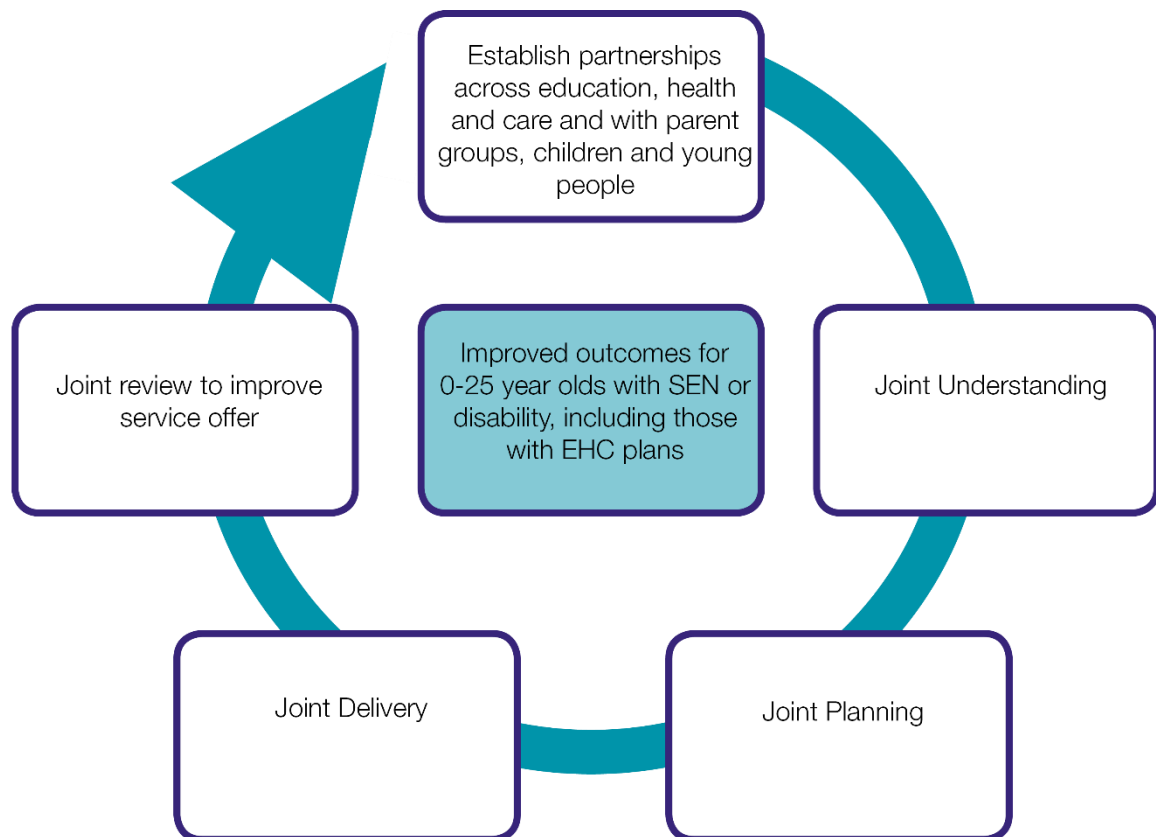
<sup>9</sup> NHS England. 2016. NHS Commissioning. <https://www.england.nhs.uk/commissioning/> [Accessed 13 May 2016].

## What is joint commissioning?

Joint commissioning is defined by Preparing for Adulthood as “A method of for two or more partner agencies to commission collaboratively to secure better outcomes for a defined population than either can achieve on their own<sup>10</sup>.”

It has five distinct stages:

1. Establishing partnerships.
2. Jointly understanding the need.
3. Jointly planning to meet this need.
4. Jointly delivering services.
5. Jointly reviewing to improve services.



<sup>10</sup> Preparing for Adulthood (2015). Joint Commissioning in action. Available to download from: <http://bit.ly/1du8oSU>