



## Commissioning children's palliative care in England: 2017 edition

Together for Short Lives' report on children's palliative care services commissioned by NHS clinical commissioning groups (CCGs) and local authorities in England

**November 2017**

## Introduction

This report describes what clinical commissioning groups (CCGs) and local authorities are claiming they do to plan, fund and monitor (a process known as 'commissioning') care for the 40,000 children with life-limiting and life-threatening conditions in England.<sup>1</sup>

Without an England-wide record of what is being funded, and where, it is difficult to understand how well children's palliative care services are being supported. This is vital, as the number of children and families who depend on these services is growing. Our ambition is to use this information to help improve the commissioning process, to highlight gaps and start to identify where it is working well so others can learn how to improve commissioning.

This report doesn't identify how much funding is provided by each CCG or local authority to services, nor the quality of service that funding supports. The data in this report provides one element to help with our goal to overcome a postcode lottery of provision across England, so that services are adequately funded and children and families receive the support they need. This report precedes Together for Short Lives' and Hospice UK's report on commissioning and funding of voluntary sector providers of palliative care (including hospices) across England. This report, which will be published on the Together for Short Lives [website](#) soon, will explore trends in the statutory funding that children's hospices receive.

During 2017, Together for Short Lives has issued freedom of information (FOI) requests to every CCG and upper-tier local authority in England, asking how they plan care and support for children who need palliative care and their families, and finding out which services they commission for them. This includes services such as children's hospices, short breaks, community children's nursing (CCN) and bereavement care. This is the second time that we have undertaken this research, having conducted a similar exercise in 2016.<sup>2</sup>

When we issued our FOI requests, we included definitions of life-limiting conditions, life-threatening conditions and children's palliative care to make sure that all CCGs and local authorities understood the purpose of our request. For CCGs, we also included definitions of step-down care and end of life care as we asked them questions specific to these terms.

We issued our FOI requests in June 2017 and followed-up with all CCGs and local authorities which did not respond or where any answers they provided were unclear. In total, 199 (94%) CCGs and 126 (83%) local authorities provided some or all the answers to our questions. We offer to continue to work with those CCGs and local authorities which have not yet responded to our FOIs to help them to do so.

We will update our [CCG](#) and [local authority](#) tables monthly as we receive more data. The results we publish here consider the answers we received before midnight on Monday 9 October 2017, therefore the results in our table may differ from those reported here.

We want to support CCGs and local authorities so that they better understand what they are responsible for commissioning, especially in relation to the government's End of Life Care Commitments. We have produced guidance to help with this process and encourage CCGs and local authorities to refer to the NICE guideline on 'End of life care for infants, children and young people with life-limiting conditions: planning and management.'<sup>3</sup>

---

<sup>1</sup> Fraser et al. (2011) Life-limiting and life-threatening conditions in children and young people in the United Kingdom. Available at: <http://bit.ly/1Qloevd>

<sup>2</sup> Together for Short Lives (2016). Commissioning Children's Palliative Care in England. Available at: <http://bit.ly/2iAOH3z>

<sup>3</sup> NICE (2016). End of life care for infants, children and young people with life-limiting conditions: planning and management. Available at: <http://bit.ly/2q9nIWA>

## Contents

Executive summary.....	5
Our recommendations.....	6
What should CCGs and local authorities do for children with life-limiting and life-threatening conditions?.....	7
What we have found .....	9
How to interpret these results .....	9
A. Lack of out of hours support for children who need palliative care .....	10
B. Out of hours community children’s nursing support.....	11
C. Are CCGs and local authorities commissioning palliative care for children and young people with life-limiting and life-threatening conditions between the ages of 0 and 25? ...	12
D. Are CCGs and local authorities commissioning short breaks for children with life-limiting and life-threatening conditions? .....	12
E. Are CCGs commissioning step-down care for children with life-limiting and life-threatening conditions? .....	13
F. Are CCGs commissioning end of life care for children with life-limiting and life-threatening conditions? .....	13
G. Are CCGs implementing the NICE clinical guideline ‘End of life care for infants, children and young people with life-limiting conditions: planning and management’? .....	13
H. Are CCGs implementing ‘Our Commitment to you for end of life care: The Government Response to the Review of Choice’ for children and young people with life-limiting and life-threatening conditions? .....	13
I. Do CCGs and local authorities have a published strategy or care pathway for children with life-limiting and life-threatening conditions? .....	14
J. Do CCGs and local authorities assess numbers and needs of children and young people with life-limiting and life-threatening conditions between the ages of 0 and 25 among the population they serve? .....	14
K. Are CCGs and local authorities jointly commissioning palliative care for children and young people with life-limiting and life-threatening conditions? .....	15
L. Are CCGs commissioning palliative care which enables a child or young person to receive end of life care at home if they wish to do so? .....	15
M. Are CCGs commissioning a rapid transfer process for children and young people with life-limiting conditions to allow urgent transfer to the preferred place (for example from the intensive care unit to their home or to a children's hospice)? .....	15
N. Are CCGs and local authorities taking steps to integrate assessments, plans and services for children and young people with life-limiting and life-threatening conditions? ..	15
O. Do CCGs offer personal budgets to children and young people with life-limiting and life-threatening conditions? .....	16
P. Are CCGs taking steps to make sure that young people with life-limiting and life-threatening conditions can access palliative care services which are appropriate to their age and developmental stage? .....	16

Q. Are CCGs taking steps to make sure that young people with life-limiting and life-threatening conditions experience smooth transitions from children's to adults' palliative care services? .....	16
R. Are CCGs commissioning services that provide a multidisciplinary team consistent with the NICE 'End of life care for infants, children and young people' clinical guideline? 17	
S. Are CCGs commissioning services that provide acute children's palliative care nurses? .....	17
T. Are CCGs commissioning services that provide community children's nurses who provide children's palliative care? .....	17
U. Are CCGs and local authorities commissioning voluntary sector children's palliative care services (including children's hospice services)? .....	18
V. Are CCGs commissioning services that provide community paediatricians who provide children's palliative care? .....	19
W. Are CCGs and local authorities commissioning emotional and psychological support for children with life-limiting and life-threatening conditions and their families? .....	19
X. Are CCGs and local authorities commissioning bereavement care for families before a child or young person aged 0-25 has died? .....	19
Y. Are CCGs and local authorities commissioning bereavement care for families after a child or young person aged 0-25 has died? .....	19
Z. Are CCGs and local authorities commissioning equipment services - including services which provide wheelchairs and services - to maintain and repair equipment? ...	20
What do we want to happen as a result of our findings? .....	20
Appendix one: Definitions .....	21
Children's palliative care.....	21
Life-limiting and life-threatening conditions .....	21
Out of hours.....	21
Step-down care .....	21
End of life care .....	21
Appendix two: Together for Short Lives' freedom of information requests of CCGs and local authorities in England.....	22
Freedom of information request to CCGs in England.....	22
Freedom of information request to local authorities in England.....	25
Appendix three: Our methodology.....	27
Appendix four: What is commissioning?.....	28
What is joint commissioning? .....	29

## Executive summary

### We found:

- 1. Children's palliative care commissioning in England is patchy and inconsistent.** This is demonstrated by the responses to each of the questions set out in our report. Most commissioners are failing to assess the numbers and needs of children with life-limiting and life-threatening conditions, which is essential to ensuring that the correct services are commissioned to support them. We found, however, that fewer than half (43%) of CCGs and just 23% of local authorities assess the numbers and needs of children who need palliative care. Despite 43% of CCGs claiming that they do this, only 4% of CCGs could tell us how many children with life-limiting and life-threatening conditions there are in their area, while only 2% of local authorities could provide this figure.
- 2. The government's end of life care choice commitment is not being fulfilled in almost half of local areas in England.** Almost half (46%) of CCGs are failing to implement the commitment and have no plans to do so. The government's response to the end of life care choice review states that 'to support high quality personalised care for children and young people, commissioners and providers of services must prioritise children's palliative care in their strategic planning' so that services can work together seamlessly and advance care planning can be shared and acted upon. Despite this, only a third (35%) of CCGs responded that they are implementing this guidance, while a further 19% stated that their plans to do so are in development.
- 3. Most CCGs have not implemented the new clinical guidance for children who need palliative care.** Fewer than a third (31%) of CCGs stated that they are currently implementing the new NICE guideline on 'End of life care for infants, children and young people with life-limiting conditions: planning and management'. A further 27% stated that their plans to implement this guidance are 'in development'. Of concern, only 29% of CCGs commission services that can provide a paediatric palliative care multidisciplinary team that meets the requirements of the guidance.
- 4. Even though many seriously ill children need care 24 hours a day, seven days a week, commissioners are failing to plan and fund this support.** Our research found a major discrepancy between services commissioned between 8am and 6:30pm Monday - Friday and services commissioned to provide care out of hours. 93% of CCGs commission community children's nursing teams, but just 67% commission them to provide care out of hours. (See [page 11](#) for full details). Although 64% of CCGs commission services to provide community paediatricians, only 29% commission them to provide out of hours care. Similarly, 95% of CCGs commission equipment services – including wheelchairs, but just 52% ensure that this support is available out of hours. This is having a negative impact on the ability of families to choose how and where their child receives care.
- 5. Many local authorities are failing to commission short breaks for children who need palliative care, despite being legally obliged to do so.** More than one in five (21%) local authorities are failing to meet their legal duty to commission short breaks for disabled children with life-limiting and life-threatening conditions. This figure has worsened in the past year; one in seven (14%) local authorities were failing to commission short breaks for these children in 2016.

6. **There is a postcode lottery of bereavement care across England for parents whose child has died.** Nearly one in five (17%) CCGs do not commission this support and nearly half (45%) do not commission this support out of hours. Local authorities are also failing to commission this support – just 28% do so, while 18% can provide this out of hours.
7. **CCGs and local authorities are failing to fund voluntary sector children’s palliative care organisations – including children’s hospices.** Nearly a quarter (22%) of CCGs do not commission these organisations, despite the crucial role they play in providing support for children with life-limiting and life-threatening conditions and their families. Nearly three quarters (72%) of local authorities do not commission these services.
8. **Too many areas still do not commission age and developmentally appropriate services for young people with life-limiting and life-threatening conditions.** Young people have specific palliative care needs which differ from both younger children and older adults. Despite this, one in six (16%) CCGs are not commissioning age and developmentally appropriate services. Furthermore, a similar proportion (15%) of CCGs do not take steps to ensure that these young people experience smooth transitions from children’s to adult palliative care services.
9. **Despite significant challenges across England, there are still some examples of commissioners reporting a broad range of children’s palliative care commissioning.** The proportion of CCGs that commission short breaks, step-down care, and out of hours equipment services has risen since our research in 2016. The proportion of local authorities that stated that they commission palliative care doubled, from 19% in 2016 to 38% in 2017. We do not know, however, how much commissioners spent commissioning these services or whether it was enough to meet need.

## Our recommendations

1. **The government should undertake a review of the children’s palliative care currently available to children with life-limiting conditions in England as a matter of urgency.** This should lead to a cross-departmental children’s palliative care strategy for achieving outcomes for children and families.
2. **CCGs and local authorities should implement the existing policy framework which describes how children’s palliative care services should be planned, funded and provided.** This includes:
  - the government’s end of life care choice commitment for children<sup>4</sup>
  - the NICE guideline<sup>5</sup> and quality standard on end of life care for children<sup>6</sup>

<sup>4</sup> Department of Health (2016). Our Commitment to you for end of life care: The Government Response to the Review of Choice in End of Life Care. Available at: <http://bit.ly/29GwFsD>

<sup>5</sup> NICE (2016). End of life care for infants, children and young people with life-limiting conditions: planning and management. Available at: <http://bit.ly/2g9nIWA>

<sup>6</sup> NICE (2017). End of life care for infants, children and young people (Quality Standard QS160). Available at: <http://bit.ly/2yBeK15>

- the Ambitions for Palliative and End of Life Care Framework<sup>7</sup>
  - Together for Short Lives' guide to jointly commissioning palliative care for children and young people aged 0 - 25<sup>8</sup>
3. **Commissioners should make sure that families can access care and support around the clock.** We would like CCGs and local authorities to recognise the importance of out of hours support for families who have a child with a life-limiting or life-threatening condition and commission services accordingly. Many of these families care for their child 24/7 and need out of hours support from community children's nurses, community paediatricians, equipment services and others.
  4. **CCGs and local authorities should adopt the recommendations of the NICE guidance.** In particular, commissioners should support the development of Managed Clinical Networks, as has happened in Wales, which will help the planning and commissioning of services to meet the needs of children and families.<sup>9</sup>
  5. **The government and NHS England should 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.
  6. **The government and NHS England should consider appropriate mechanisms to bridge the children's palliative care accountability gap.** They should develop a system to monitor how CCGs and local authorities are supporting children's palliative care in accordance with their legal duties.

### **What should CCGs and local authorities do for children with life-limiting and life-threatening conditions?**

The National Institute for Health and Care Excellence (NICE) 'End of life care for infants, children and young people with life-limiting conditions: planning and management' clinical guidance that was published in December 2016 sets out the range of services that children and young people should be able to access.<sup>10</sup> Many of the questions set out in this research relate to the services described in this guidance. Commissioners are expected to meet all the requirements of new NICE guidance, though this is not mandated by NHS England.

Following the publication of this guideline, NICE published the quality standard on 'End of life care for infants, children and young people', which describe what high quality palliative care is for babies, children and young people with life-limiting and life-threatening conditions.<sup>11</sup> The quality standard comprises six quality statements that children and families should be entitled to:

<sup>7</sup> NHS England (2015). Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020. Available at: <http://bit.ly/2w3dOzD>

<sup>8</sup> Together for Short Lives (2015). Jointly commissioning palliative care for children and young people aged 0-25 including short breaks. Available at: <http://bit.ly/2cgEAXR>

<sup>9</sup> Together for Short Lives. All Wales Managed Clinical Network. Available at: <http://bit.ly/2k3Vflc>

<sup>10</sup> NICE (2016). End of life care for infants, children and young people with life-limiting conditions: planning and management. Available at: <http://bit.ly/2g9nIWA>

<sup>11</sup> NICE (2017). End of life care for infants, children and young people (Quality Standard QS160). Available at: <http://bit.ly/2yBeK15>

1. Children with life-limiting conditions and their parents or carers should be involved in developing an advance care plan (ACP).
2. Children should have a named medical specialist who leads and coordinates their care.
3. Children and their parents or carers should be given information about emotional and psychological support, including how to access it.
4. Children should be cared for by a multidisciplinary team that includes members of a specialist children's palliative care team.
5. Parents or carers of children approaching the end of life should be offered support for grief and loss, including after their child has died.
6. Children approaching the end of life and being cared for at home should have 24-hour access to both children's nursing care and advice from a consultant in children's palliative care.

While it is not mandatory for planners, funders and providers of health and social care to implement the quality standard, NICE states that they should aim to achieve the quality standard in their local context.

In 'Our Commitment to you for End of Life Care: The Government Response to the Review of Choice in End of Life Care', the Department of Health set out what they expect commissioners to achieve for children who need palliative care.<sup>12</sup> This includes:

- short breaks (respite care), delivered either in a children's hospice setting or at home by community palliative care services, or by 'hospice at home' services
- good collaboration between different clinical and non-clinical services across a variety of different settings
- support around bereavement, both before and after a child dies
- prioritisation of children's palliative care in commissioners' strategic planning so that services can work together seamlessly and advance care planning can be shared and acted upon

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>13</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 special educational needs and disabilities (SEND).

The Short Breaks Regulations<sup>14</sup> set out how local authorities in England **must** provide breaks from caring for parents/carers of disabled children. Breaks should support

<sup>12</sup> Department of Health (2016). Our Commitment to you for end of life care: The Government Response to the Review of Choice in End of Life Care. Available at: <http://bit.ly/29GwFsD>

<sup>13</sup> Department for Education (2014). Special educational needs and disability code of practice: 0 to 25 years. Available at: <http://bit.ly/1kOCi5j>

<sup>14</sup> Department for Education (2011). Short breaks for carers of disabled children: departmental advice for local authorities. Available at: <http://bit.ly/1EmRyvM>

parents/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 all 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. Provide parents with a short breaks services statement detailing the range of available breaks and any eligibility criteria attached to them.

## **What we have found**

### ***How to interpret these results***

For each question in this report, we asked CCGs and local authorities for a binary 'Yes/No' answer. This means that each 'Yes' response does not indicate the same level of commissioning or funding, only whether this service is being commissioned at all.

Commissioning involves each authority assessing the numbers and needs of its population, funding services accordingly and monitoring the outcomes it achieves. It includes:

- 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

A full explanation of this can be found in Together for Short Lives' 'Jointly Commissioning Children's Palliative Care for Children and Young People Aged 0-25' guide.<sup>15</sup> An overview of the commissioning process is available in [Appendix four](#).

It is important to note, therefore, that a 'Yes' response to any of our questions does not describe the quality of the commissioning by each CCG or local authority, how much it is spending on these contracts or whether it is commissioning sufficient services to meet the needs of its population.

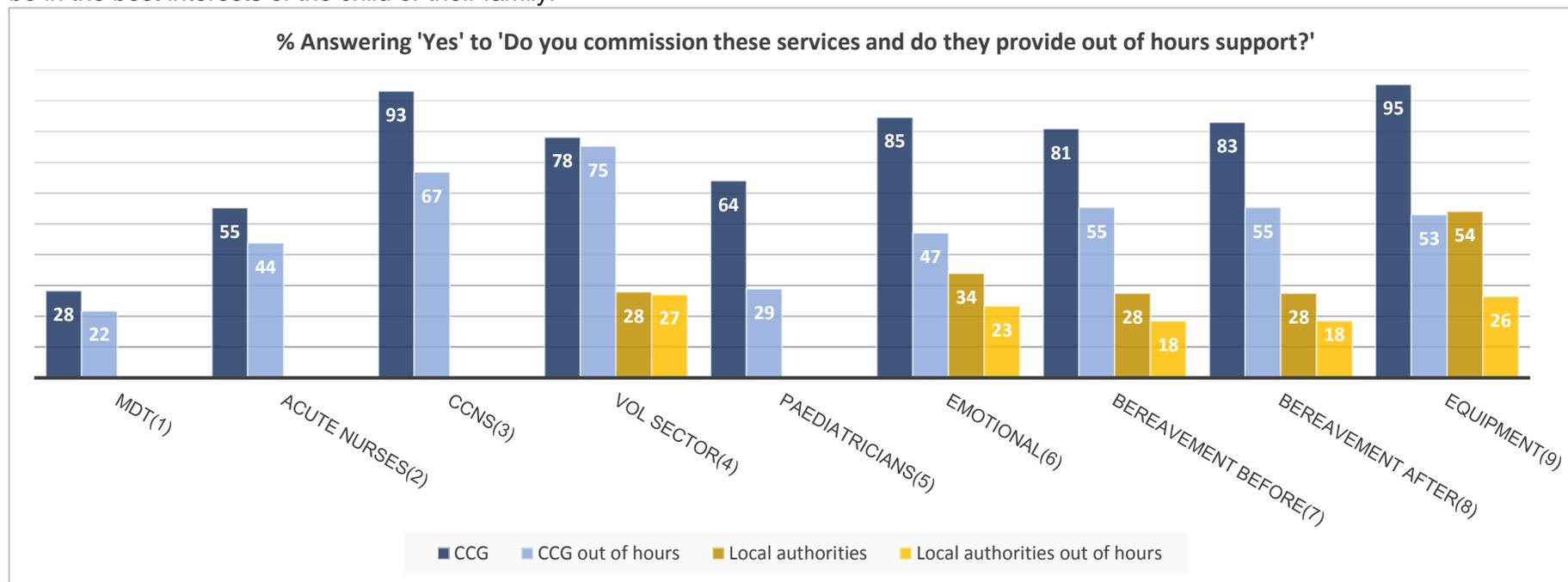
---

<sup>15</sup> Together for Short Lives (2015). Jointly commissioning palliative care for children and young people aged 0-25 including short breaks. Available at: <http://bit.ly/2cgEAXR>

### A. Lack of out of hours support for children who need palliative care

For many of the services that we enquired about, we asked CCGs and local authorities whether they commission these services to provide care [out of hours](#) as well as in normal working hours (8am to 6:30pm).

Life-limiting and life-threatening conditions in children and young people are often complex and unpredictable. Children and young people will often need palliative care throughout the day and night. Where clinically appropriate, the best place for a child to access palliative care is in the place they or their family choose. This may be at home, in a children’s hospice or another setting. An emergency admission to hospital may not be in the best interests of the child or their family.



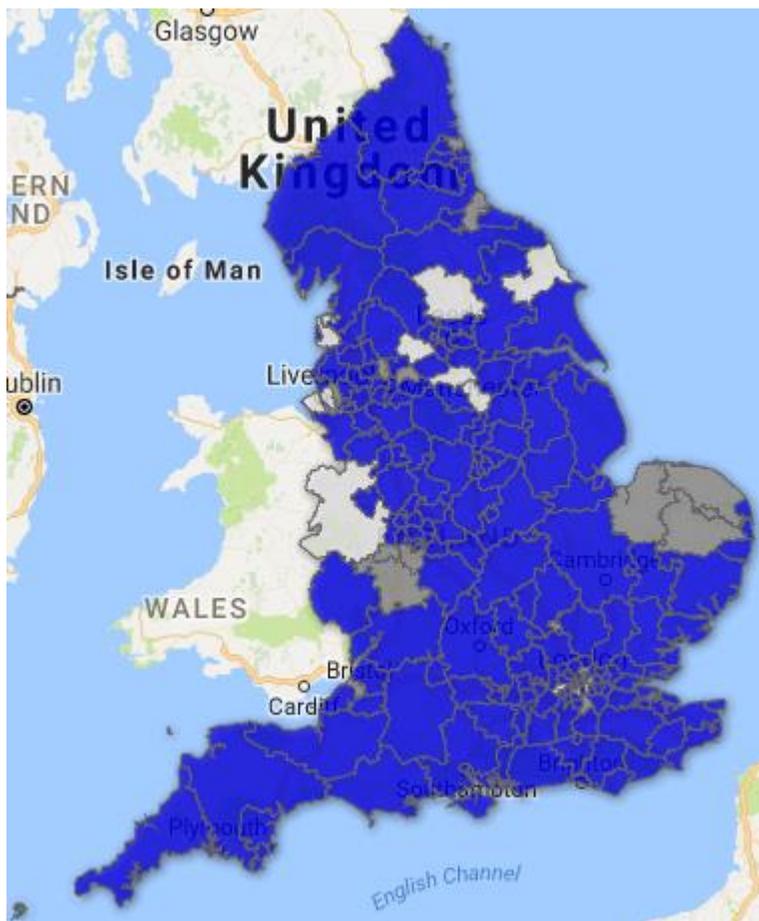
Links to full responses:

- (1) [Multidisciplinary team](#)
- (2) [Acute nurses](#)
- (3) [Community children’s nurses](#)
- (4) [Voluntary sector organisations](#)
- (5) [Community paediatricians](#)
- (6) [Emotional and psychological support](#)
- (7) [Bereavement care before a child has died](#)
- (8) [Bereavement care after a child has died](#)
- (9) [Equipment services](#)

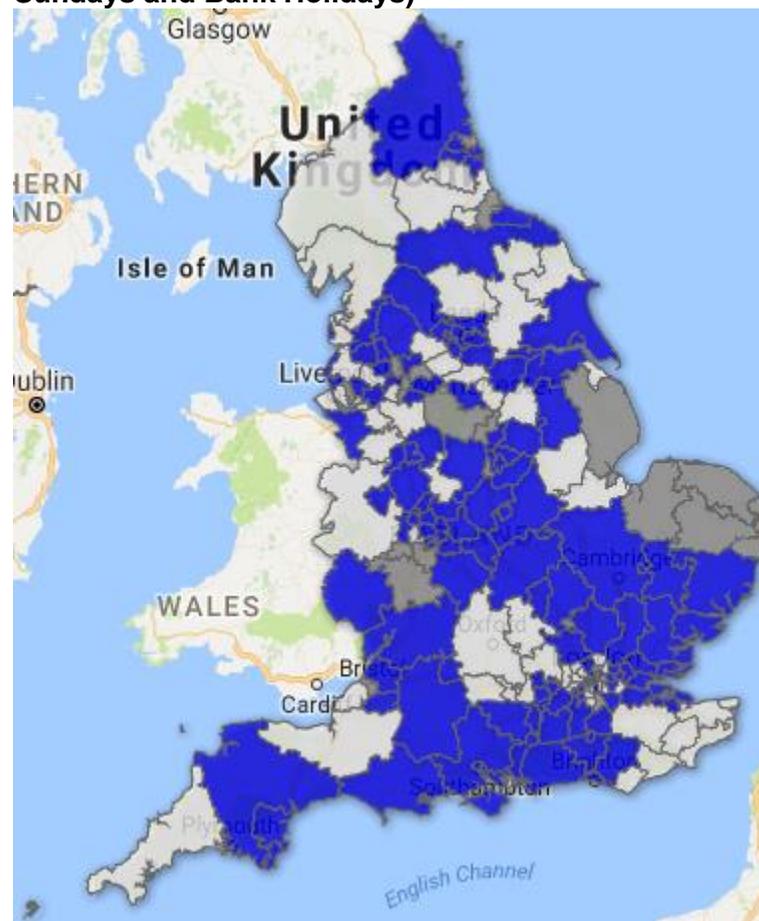
### **B. Out of hours community children's nursing support**

We have found that 93% of CCGs commission CCNs to provide palliative care to children with life-limiting conditions during normal working hours. However, just 67% commission them to provide care out of hours. The maps below show the difference in coverage across England (blue=yes, white=no, grey=no response received). For further details, see the [community children's nursing analysis](#) section.

**CCG areas that commission community children's nurses during working hours (8am - 6:30pm)**



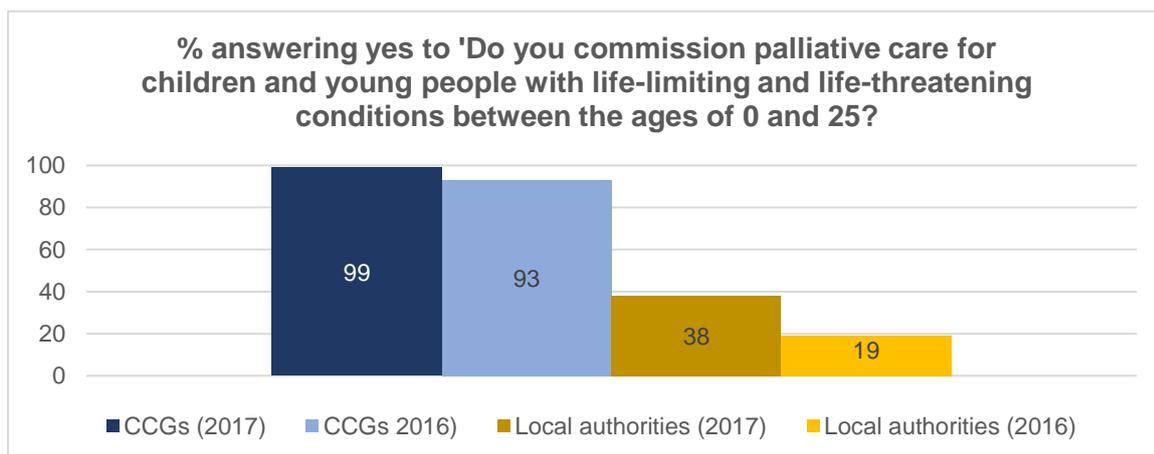
**CCG areas that commission community children's nurses out of hours (6:30pm - 8am on weekdays and all day on Saturdays, Sundays and Bank Holidays)**



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

Of those that responded to this question, 99% of CCGs responded that they do commission children’s palliative care, while only 38% of local authorities reported that they do. This was despite us clearly defining that children’s palliative care includes social care, such as short breaks for respite, to help local authorities to answer this question.

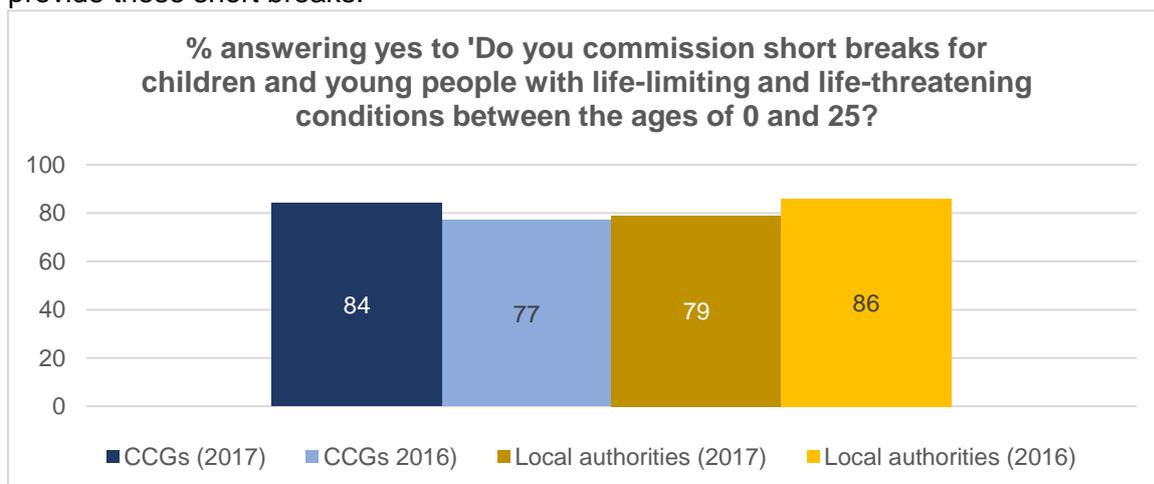
This did, however, mark a significant improvement from our results in 2016, where 93% of CCGs and 19% of local authorities responded positively to this question.<sup>16</sup>



**D. Are CCGs and local authorities commissioning short breaks for children with life-limiting and life-threatening conditions?**

84% of CCGs reported that they commission short breaks for children who need palliative care, which is an increase from our 2016 research, when just 77% commissioned these services.

However, more than one in five (21%) local authorities do not commission short breaks for children with life-limiting and life-threatening conditions, despite having a legal duty to do so. This figure has declined since 2016, when one in seven (14%) reported that they do not provide these short breaks.



<sup>16</sup> Together for Short Lives (2016). Commissioning Children’s Palliative Care in England. Available at: <http://bit.ly/2iAOH3z>

**E. Are CCGs commissioning step-down care for children with life-limiting and life-threatening conditions?**

Three quarters (75%) of CCGs commission step-down care for children who need palliative care. This is an improvement from 2016, where the figure was 68%.

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. For further information, see [definitions](#).

**F. Are CCGs commissioning end of life care for children with life-limiting and life-threatening conditions?**

93% of CCGs reported that they commission end of life care for children with life-limiting and life-threatening conditions, which is a slight increase from the number which responded positively in our 2016 research (92%).

**G. Are CCGs implementing the NICE clinical guideline 'End of life care for infants, children and young people with life-limiting conditions: planning and management'?**

The NICE 'End of life care for infants, children and young people with life-limiting conditions: planning and management' guideline states:

'Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it.'<sup>17</sup>

Despite this, only three in ten (31%) CCGs state that they are currently implementing this guidance, while a further 27% responded that their plans to do so are in development.

Although many CCGs responded that it is down to individual providers of health and social care implement the guideline, this contradicts the government's position. In March 2017, Lord Carlile of Berriew submitted a written question in Parliament:

"To ask Her Majesty's Government what steps they will take to ensure that Clinical Commissioning Groups are accountable to NHS England for delivering a consistent level of children's palliative care across England."<sup>18</sup>

The minister's response to this was that:

"NHS England expects clinical commissioning groups to commission services in accordance with the National Institute for Health and Care Excellence guideline End of life care for infants, children and young people with life-limiting conditions"

**H. Are CCGs implementing 'Our Commitment to you for end of life care: The Government Response to the Review of Choice' for children and young people with life-limiting and life-threatening conditions?**

The government's response to the Choice Review states that:

'To support high quality personalised care for children and young people, commissioners and providers of services must prioritise children's palliative care in their strategic planning

---

<sup>17</sup> NICE (2016). End of life care for infants, children and young people with life-limiting conditions: planning and management. Available at: <http://bit.ly/2g9nIWA>

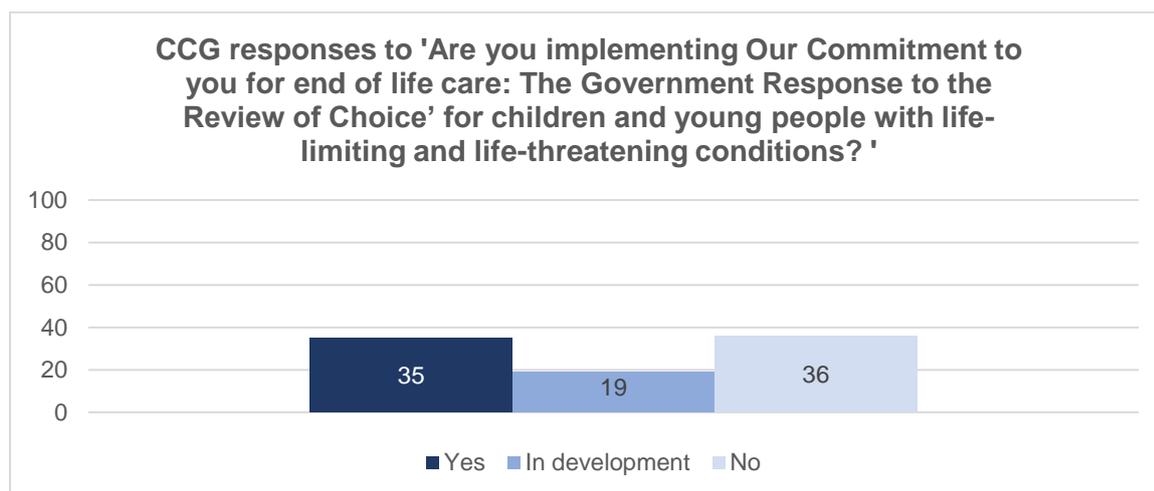
<sup>18</sup> Hansard (2017). Oral Question HL6151 from Lord Carlile of Berriew. Asked on 16 March 2017. Available at: <http://bit.ly/2xQvAtH>

so that services can work together seamlessly and advance care planning can be shared and acted upon.

Commissioners should also consider how they can structure services that offer accessible, high quality respite and bereavement support for children and their families.'

Despite this, only a third (35%) of CCGs responded that they are implementing this guidance, while a further 19% stated that their plans to do so are in development.

This means that almost half (46%) of CCGs are failing to implement the government's end of life care choice commitment to children and have no plans to do so.



**I. Do CCGs and local authorities have a published strategy or care pathway for children with life-limiting and life-threatening conditions?**

Just 17% of CCGs have a published strategy or care pathway for children who need palliative care, though a further 18% reported that they are in the process of developing this. Just 11% of local authorities stated that they have such a strategy or pathway.

**J. Do CCGs and local authorities assess numbers and needs of children and young people with life-limiting and life-threatening conditions between the ages of 0 and 25 among the population they serve?**

The number of children and young people with life-limiting conditions is increasing. Children's palliative care charities want to provide vital care for every child who needs it, but state funding is not keeping pace with demand.

For example, a 2015 report showed a 50% increase over a 10-year period in the number of children and young people with life-limiting conditions in Scotland; their numbers have risen from 4,334 in 2004 to 6,661 in 2014.<sup>19</sup> This is a dramatic rise; if it had been replicated across the UK as a whole, the number of children and young people with life-limiting conditions in England could be much more than the current estimate of nearly over 40,000.<sup>20</sup>

Assessing the needs of the local population is essential to ensuring correct planning for services that are needed. We were disappointed to find, therefore, that just 43% of CCGs

<sup>19</sup> Fraser et al. (2015). Children in Scotland requiring Palliative Care: identifying needs and numbers. Available at: <http://bit.ly/1Krn2EU>

<sup>20</sup> Fraser et al. (2011) Life-limiting and life-threatening conditions in children and young people in the United Kingdom. Available at: <http://bit.ly/1Qloevd>

and 23% of local authorities confirmed that they assess the numbers and needs of children who need palliative care.

Despite 43% of CCGs claiming that they do this, only 4% of CCGs could tell us how many children with life-limiting and life-threatening conditions there are in their area. Similarly, only 2% of local authorities could provide this figure.

***K. Are CCGs and local authorities jointly commissioning palliative care for children and young people with life-limiting and life-threatening 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>21</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 special educational needs and disabilities (SEND).

Despite this, only 68% of CCGs reported that they commission services for children with life-limiting and life-threatening conditions jointly with their local authorities. Fewer than half (49%) of local authorities reported that they jointly commission these services with CCGs.

Together for Short Lives has produced guidance for CCGs and local authorities on [jointly commissioning palliative care for children and young people](#).

***L. Are CCGs commissioning palliative care which enables a child or young person to receive end of life care at home if they wish to do so?***

Most CCGs (94%) responded that they commission palliative care which enables children or young people to receive end of life care at home if this is their wish.

***M. Are CCGs commissioning a rapid transfer process for children and young people with life-limiting conditions to allow urgent transfer to the preferred place (for example from the intensive care unit to their home or to a children's hospice)?***

Although most CCGs responded that they do commission palliative care that enables a child or young person to receive end of life care at home, this is often dependent on whether there is a rapid transfer process commissioned, which can transport children, for example, from the intensive care unit to their home.

Less than two thirds (64%) of CCGs confirmed that they commission this service, which is far lower than those that reported that they support children to be able to die at home (94%).

***N. Are CCGs and local authorities taking steps to integrate assessments, plans and services for children and young people with life-limiting and life-threatening conditions?***

Children and young people with life-limiting and life-threatening conditions will often be cared for by a wide range of authorities, services and professionals. It is vital, therefore, that assessments, plans and services are integrated to relieve the administrative burden for families, many of whom will find it difficult to leave the house for appointments due to their child's condition and needs.

Most (85%) of CCGs reported that they integrate assessments, plans and services in this way, while less than three quarters (72%) of local authorities reported that they do so.

---

<sup>21</sup> Department for Education. 2014. Special educational needs and disability code of practice: 0 to 25 years. Available to download from: <http://bit.ly/1kOCi5j>

**O. Do CCGs offer personal budgets to children and young people with life-limiting and life-threatening conditions?**

A personal budget is a sum of money that is made available to someone who needs support. The money comes from their local authority social care or education department or NHS commissioners and is allocated to the individual or family to spend on help and support to meet their assessed eligible needs and to achieve agreed outcomes.

Nearly all (96%) of CCGs reported that they offer personal budgets to children and young people who need palliative care.

**P. Are CCGs taking steps to make sure that young people with life-limiting and life-threatening conditions can access palliative care services which are appropriate to their age and developmental stage?**

Young people with life-limiting conditions have specific needs which differ from both younger children and older adults. However, there is a lack of age and developmentally-appropriate palliative care services which can meet this growing demand.

It's also hard for these young people to get the support they need beyond their health needs, to do all the other things that all teenagers want to do: going out, living independently, having relationships, exploring their sexuality or entering the world of work and further education. Young people face too many barriers and obstacles, making it impossible for them to get on with enjoying adulthood. They need help now; they don't have the luxury of time on their hands.

We were disappointed to find, therefore, that nearly one in six (16%) CCGs do not make sure that young people can access age and developmentally appropriate services.

**Q. Are CCGs taking steps to make sure that young people with life-limiting and life-threatening conditions experience smooth transitions from children's to adults' palliative care services?**

Becoming a young adult should be an exciting time, full of new experiences and a time to look forward to a new adventure. But for young people with life-limiting conditions, making the transition from children's to adult services is like falling off a cliff edge.

Medical advances mean more young people with life-limiting conditions are living into adulthood. There are 55,000 young adults aged between 18 and 40 with life-limiting conditions and this figure continues to grow.<sup>22</sup>

This is cause to celebrate. However, the transition these young people have to undergo from the comprehensive care offered by children's palliative care to unfamiliar adults' services can be daunting and is often not joined up. Young people with life-limiting conditions must forge relationships with new agencies and professionals, and for many young people, this transition coincides with a rapid decline of their condition.

As with age and developmentally appropriate services, we were disappointed to find that only 85% of CCGs responded positively, which means that nearly one in 6 (15%) of CCGs do not take steps to ensure young people with life-limiting and life-threatening conditions experience smooth transitions from children's to adult palliative care services. This is slightly higher than the figure from 2016 (83%).

---

<sup>22</sup> Fraser et al. (2013). Prevalence of life-limiting and life-threatening conditions in young adults in England 2000-2010. Available at: <http://bit.ly/2zp2rGy>

**R. Are CCGs commissioning services that provide a multidisciplinary team consistent with the NICE ‘End of life care for infants, children and young people’ clinical guideline?**

The NICE ‘End of life care for infants, children and young people with life-limiting conditions: planning and management’ guidance recommends that a multidisciplinary specialist paediatric palliative care team should include, at a minimum:

- a paediatric palliative care consultant
- a nurse with expertise in paediatric palliative care
- a pharmacist with expertise in specialist paediatric palliative care
- experts in child and family support who have experience in end of life care (for example in providing social, practical, emotional, psychological and spiritual support)<sup>23</sup>

We asked each CCG whether they commissioned services that could provide this. We found that currently just 29% of CCGs are able to offer this, while only 22% can provide this out of hours.

**S. Are CCGs commissioning services that provide acute children’s palliative care nurses?**

Children with life-limiting and life-threatening conditions receive care in a range of settings – in the community, at children’s hospices and in the acute sector.

Our research found, however, that just 55% of CCGs commission services which provide acute children’s palliative care nurses, while just 44% of CCGs commission services that can provide this care out of hours.

**T. Are CCGs commissioning services that provide community children’s nurses who provide children’s palliative care?**

Children with life-limiting or life-threatening conditions also need to get the support they need, when they need it, in their communities from community children’s nursing teams. In 2011 the Department of Health described community children’s nurses as the ‘bedrock of the pathways of care’ for four groups of children, which included children with life-limiting and life-threatening illnesses.<sup>24</sup>

The Royal College of Nursing (RCN) recommends that for an average-sized district, with a child population of 50,000, a minimum of 20 whole time equivalent (WTE) community children’s nurses are required to provide a holistic community children’s nursing service.<sup>25</sup> The Office of National Statistics estimates that there are 13,770,873 children aged 0 - 18 in England.<sup>26</sup> If the RCN recommendation were to be met, this would therefore require

---

<sup>23</sup> NICE (2016). End of life care for infants, children and young people with life-limiting conditions: planning and management. P31. Available at: <http://bit.ly/2g9nIWA>

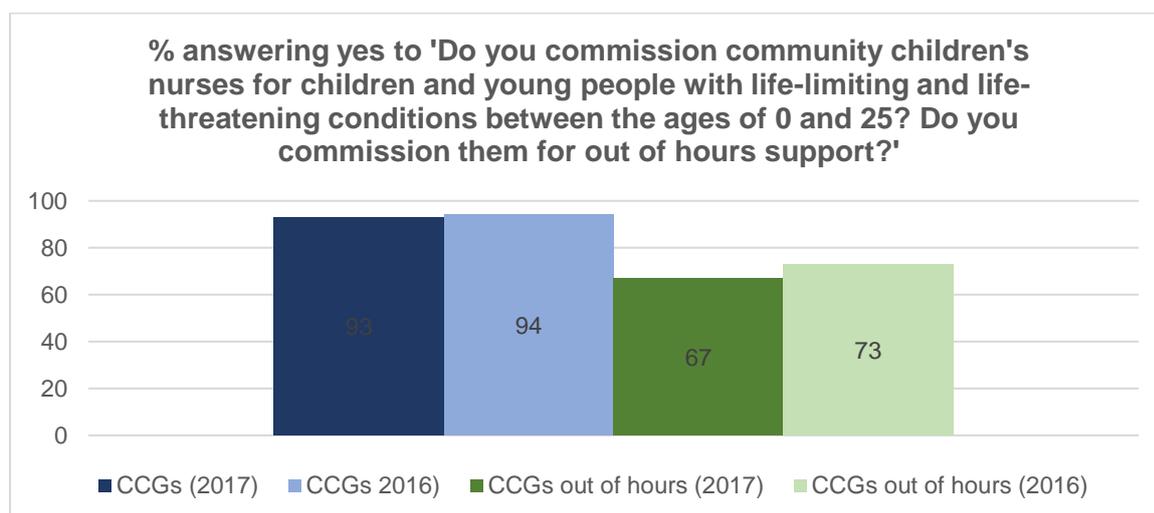
<sup>24</sup> DH (2011). NHS at Home: Community Children’s Nursing Services. P3. Available to download from <http://bit.ly/10zZtZV>.

<sup>25</sup> RCN (2014). The future for community children’s nursing: challenges and opportunities. P.10. Available to download from: <http://bit.ly/1QgLhZb>.

<sup>26</sup> ONS (2016). Population Estimates Analysis Tool: Mid-2015. ‘Persons UK’ tab. Available to download from: <http://bit.ly/2iJOTgS>.

approximately 5,508 community children’s nurses. There are currently just 522 community children’s nurses in England, which is just 10% of this total.<sup>27</sup>

Of the CCGs that responded to our FOI request, 93% stated that they commission services that provide community children’s nurses, which is a marginal decrease from our 2016 research (94%). However, crucially only two thirds (67%) of CCGs commission services that require this support to be available out of hours. This means that families are unable to access the care that they need at home whenever they need it and represents a significant decrease from our 2016 findings (73%).



**U. Are CCGs and local authorities commissioning voluntary sector children’s palliative care services (including children’s hospice services)?**

Voluntary sector children’s palliative care services, including children’s hospices, provide lifeline support for children with life-limiting and life-threatening conditions – and their families.

However, a 2011 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.<sup>28</sup>

Together for Short Lives’ own research found that the level of statutory funding for children’s hospices has fallen for the past two years and is now just 22% of their overall charitable costs. In the past year alone, local authority funding for children’s hospices fell by 61%.<sup>29</sup>

Of the CCGs that responded to our FOI request, 78% stated that they commission voluntary sector children’s palliative care providers and nearly all of those (75%) commission these services for out of hours support.

For local authorities however, these figures were far lower. Just 28% of local authorities commission these services, while 27% commission them to provide care out of hours.

In 2016, 82% of CCGs and just 18% of local authorities stated that they commission these services, though it should be noted that our 2016 research question asked only if they

<sup>27</sup> NHS Digital (2017). NHS Workforce Statistics – June 2017, Provisional statistics: Staff Group, Area and Level. Available to download from: <http://bit.ly/2gB9v84>.

<sup>28</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 at: <http://bit.ly/XQBIE7>.

<sup>29</sup> Together for Short Lives (2016). On the brink: a crisis in children’s palliative care funding in England. Available at: <http://bit.ly/2f7HowK>

commissioned 'children's hospices' rather than 'voluntary sector organisations, including children's hospices.

***V. Are CCGs commissioning services that provide community paediatricians who provide children's palliative care?***

Of the CCGs that responded to this question, fewer than two thirds (64%) of CCGs commission services that provide community paediatricians that deliver children's palliative care. Worryingly, a much lower proportion (29%) of CCGs commission services which can provide this support out of hours.

***W. Are CCGs and local authorities commissioning emotional and psychological support for children with life-limiting and life-threatening conditions and their families?***

Although most CCGs (85%) responded that they commission services that provide emotional and psychological support for children and families, just 47% commission services that can provide this care out of hours.

The figures for local authorities are far lower. Just a third (34%) of local authorities commission services to provide this care, while fewer than a quarter (23%) commission services to provide this out of hours.

***X. Are CCGs and local authorities commissioning bereavement care for families before a child or young person aged 0-25 has died?***

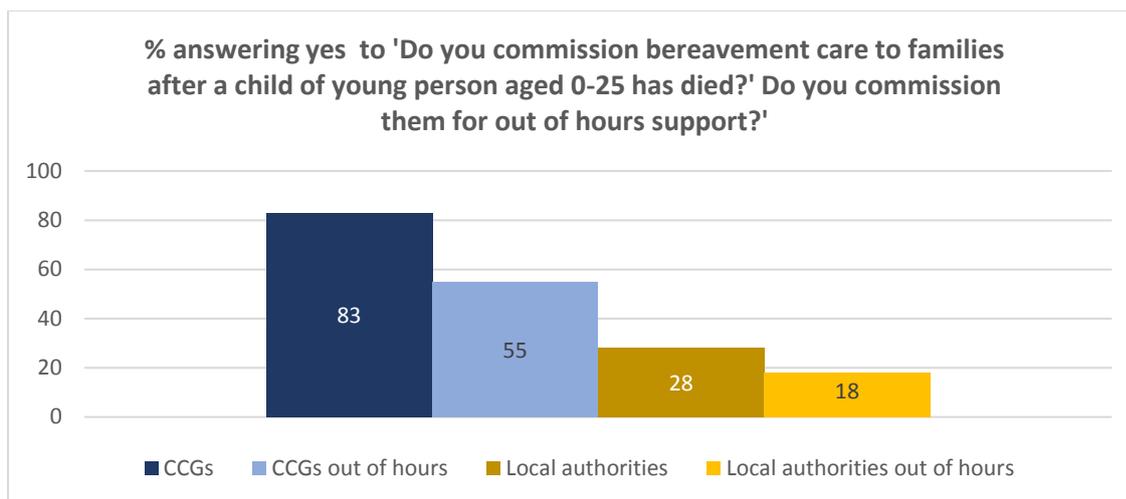
The NICE 'End of life care for infants, children and young people with life-limiting conditions: planning and management' clinical guidance recommends that bereavement support should be offered 'from a professional with appropriate expertise to the parents or carers **both before and after** the death of a child or young person.'

Of the CCGs that responded to our FOI request, one in five (19%) do not offer this support, while nearly half (45%) do not offer this out of hours. Only 28% of local authorities offer this support, while just 18% can offer this out of hours.

***Y. Are CCGs and local authorities commissioning bereavement care for families after a child or young person aged 0-25 has died?***

The proportion of CCGs that can offer bereavement care after a child or young person has died is slightly higher than those that can offer it before they have died (83%). However, only 55% can offer this care out of hours.

For local authorities, the figures are identical to those for bereavement care before a child or young person has died – 28% during 'normal working hours' and just 18% out of hours.



**Z. Are CCGs and local authorities commissioning equipment services - including services which provide wheelchairs and services - to maintain and repair equipment?**

Encouragingly, 95% of CCGs that responded to this question stated that they do commission these services. However, just 53% of CCGs commission equipment services that are available to families out of hours. This is an increase from 2016, when just 38% of CCGs commissioned services to be available out of hours.

Just over half of local authorities (54%) commission these services, while just a quarter (26%) commission these services to be available out of hours. This is almost identical to our 2016 results, where 54% of local authorities stated that they commission these services and 24% said they commission them to provide out of hours support.

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

In publishing this report and the results of our survey, we want to work with government, NHS England, CCGs and local authorities to:

- identify national trends in children’s palliative care commissioning
- identify which services are being routinely commissioned and which are not
- identify local gaps in commissioning
- encourage CCGs and local authorities to work together to jointly commission and fund holistic children’s palliative care
- encourage the public to urge their local MPs to ask CCGs and local authorities to improve local children’s palliative care commissioning
- make sure that commissioners are aware of the support that Together for Short Lives can offer them to make sure that children with life-limiting and life-threatening conditions can access the full range of services that they need – where and when they need them

## **Appendix one: Definitions**

All the definitions below were provided to CCGs when we issued our freedom of information requests. All but the definitions of step-down care and end of life care were sent to local authorities, as their questionnaire did not include these questions (see [Appendix two](#)).

### ***Children's palliative care***

An active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the family. It includes the management of symptoms, provision of short breaks and care through death and bereavement.

### ***Life-limiting and life-threatening conditions***

Life-limiting conditions are those for which there is no reasonable hope of cure and from which children will die. Some of these conditions cause slow deterioration over time rendering the child increasingly dependent on parents and carers.

Life-threatening conditions are those for which curative treatment may be feasible but can fail, such as cancer.

### ***Out of hours***

We sent each CCG and local authority our definition of out of hours, which is used throughout this report:

"We define 'out of hours and at weekends' as 6:30pm - 8am on weekdays and all day on Saturdays, Sundays and Bank Holidays."

### ***Step-down care***

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

### ***End of life care***

Care that helps all those with advanced, progressive, incurable illness, to live as well as possible until they die. It focuses on preparing for an anticipated death and managing the end stage of a terminal medical condition.

This includes care during and around the time of death, and immediately afterwards. It enables the supportive and palliative care needs of both child/young person and the family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support and support for the family into bereavement.

**For more information please see the [Together for Short Lives website](#).**

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

### ***Freedom of information request to CCGs in England***

Please note that this request was sent with the definitions as described in [Appendix one](#).

1. Do you commission palliative care for children and young people with life-limiting and life-threatening conditions between the ages of 0 and 25? (yes/no) If yes, how much did you spend on children's palliative care in 2016/17?
2. Do you have a published strategy or care pathway for children with life-limiting and life-threatening conditions? If so, please provide a link or an attachment.
3. Did you ask for your local sustainability and transformation plan to include palliative care for children with life-limiting and life-threatening conditions? (Yes/No).
4. Do you assess numbers and needs of children and young people with life-limiting and life-threatening conditions between the ages of 0 and 25 among the population you serve (yes/no)? If yes, please tell us how. Please also tell us how many children and young people with life-limiting and life-threatening conditions there are in your area.
5. Do you jointly commission palliative care for children and young people with life-limiting and life-threatening conditions between the ages of 0 and 25 with your local authorities in a way which is consistent with the Children and Families Act 2014? (yes/no)
6. Do you commission palliative care which enables a child or young person to receive end of life care at home if they wish to do so? (yes/no)
7. Do you commission a rapid transfer process for children and young people with life-limiting conditions to allow urgent transfer to the preferred place (for example from the intensive care unit to their home or to a children's hospice)? (yes/no)
8. Do you take steps to integrate assessments, plans and services for children and young people with life-limiting and life-threatening conditions between the ages of 0 and 25, including those without a special educational need and disability (yes/no)? If yes, please tell us how (For example, using education, health and care plans).
9. Do you offer personal budgets to children and young people with life-limiting and life-threatening conditions? If yes, how many children and young people with life-limiting and life-threatening conditions in your area have a personal budget?
10. Do you take steps to make sure that young people with life-limiting and life-threatening conditions can access palliative care services which are appropriate to their age and developmental stage (yes/no)? If yes, please tell us how.
11. Do you take steps to make sure that young people with life-limiting and life-threatening conditions experience smooth transitions from children's to adults' palliative care services (yes/no)? If yes, please tell us how.
12. Do you commission any of the following services for children with life-limiting or life-threatening conditions? If yes, please state which outcomes you ask service providers to achieve and how much you spent on them in 2016/17:
  - A level 4 paediatric palliative care consultant (yes/no)?

- Consistent with the NICE clinical guideline 'End of Life Care for Infants, Children and Young people', a multidisciplinary team that includes the following as a minimum (yes/no)?
    - a paediatric palliative care consultant
    - a nurse with expertise in paediatric palliative care
    - a pharmacist with expertise in specialist paediatric palliative care
    - experts in child and family support who have experience in end of life care (for example in providing social, practical, emotional, psychological and spiritual support)
  - Acute children's palliative care nurses who provide children's palliative care (yes/no)?
  - Community children's nurses who provide children's palliative care (yes/no)?
  - Voluntary sector children's palliative care services (including children's hospice services) (yes/no)? If yes, which voluntary sector services do you commission and how much did you spend on them in 2016/17?
  - Community paediatricians who provide children's palliative care (yes/no)?
  - Emotional and psychological support for children and their families (yes/no)?
  - Bereavement care - to families *before* a child under the age of 1 has died (yes/no)?
  - Bereavement care - to families *after* a child under the age of 1 has died (yes/no)?
  - Bereavement care - to families *before* a child or young person aged 1 - 25 has died (yes/no)?
  - Bereavement care - to families *after* a child or young person aged 1 - 25 has died (yes/no)?
  - Equipment - including services which provide wheelchairs and services to maintain and repair equipment (yes/no)?
13. Do you commission any of the following services to provide care out of hours and at weekends for children with life-limiting or life-threatening conditions? We define 'out of hours and at weekends' as 6:30pm - 8am on weekdays and all day on Saturdays, Sundays and Bank Holidays.
- A level 4 paediatric palliative care consultant (yes/no)?
  - Consistent with the NICE clinical guideline 'End of Life Care for Infants, Children and Young people', a multidisciplinary team that includes as a minimum:
    - a paediatric palliative care consultant
    - a nurse with expertise in paediatric palliative care
    - a pharmacist with expertise in specialist paediatric palliative care
    - experts in child and family support who have experience in end of life care (for example in providing social, practical, emotional, psychological and spiritual support)

- Acute children's palliative care nurses who provide children's palliative care (yes/no)?
  - Community children's nurses who provide children's palliative care (yes/no)?
  - Voluntary sector children's palliative care services (including children's hospice services) (yes/no)? If yes, which voluntary sector services do you commission and how much did you spend on them in 2016/17?
  - Community paediatricians who provide children's palliative care (yes/no)?
  - Emotional and psychological support for children and their families (yes/no)?
  - Bereavement care - to families *before* a child under the age of 1 has died (yes/no)?
  - Bereavement care - to families *after* a child under the age of 1 has died (yes/no)?
  - Bereavement care - to families *before* a child or young person aged 1 – 25 has died (yes/no)?
  - Bereavement care - to families *after* a child or young person aged 1 – 25 has died (yes/no)?
  - Equipment - including services which provide wheelchairs and services to maintain and repair equipment (yes/no)?
14. Do you commission the following services to children and young people with life-limiting and life-threatening conditions between the ages of 0 and 25 (yes/no)? If yes, please state how much you spent on them in 2016/17:
- short breaks (respite)
  - step-down care
  - end of life care
15. Are you implementing the NICE clinical guideline 'End of Life Care for Infants, Children and Young People: Planning and Management' (yes/no)? If yes, please tell us about the steps you are taking.
16. Are you implementing 'Our Commitment to you for end of life care: The Government Response to the Review of Choice' for children and young people with life-limiting and life-threatening condition? (yes/no). If yes, please tell us about the steps you are taking.

## ***Freedom of information request to local authorities in England***

Please note that this request was sent with the definitions as described in [Appendix one](#).

1. Do you commission palliative care for children and young people with life-limiting and life-threatening conditions between the ages of 0 and 25? (yes/no)
2. Do you have a published strategy or care pathway for children with life-limiting and life-threatening conditions? If so, please provide a link or an attachment.
3. Does your local sustainability and transformation plan set out what support will be available for children with life-limiting and life-threatening conditions? (Yes/No).
4. Do you assess numbers and needs of children and young people with life-limiting and life-threatening conditions between the ages of 0 and 25 among the population you serve (yes/no)? If yes, please tell us how you assess this and how many children and young people with life-limiting and life-threatening conditions there are in your area.
5. Do you jointly commission palliative care for children and young people with life-limiting and life-threatening conditions between the ages of 0 and 25 with your local clinical commissioning groups in a way which is consistent with the Children and Families Act 2014? (yes/no)
6. Do you take steps to integrate assessments, plans and services for children and young people with life-limiting and life-threatening conditions between the ages of 0 and 25 (yes/no)? If yes, please tell us how.
7. Do you commission short breaks (respite) for children and young people with life-limiting and life-threatening conditions between the ages of 0 and 25 (yes/no)? If yes, please state how much you spent on this in 2017/18.
8. Do you commission any of the following services for children with life-limiting or life-threatening conditions? If yes, please state which outcomes you ask service providers to achieve and how much you spent on them in 2016/17:
  - Voluntary sector children's palliative care services (including children's hospice services) (yes/no)? If yes, which voluntary sector services do you commission and how much did you spend on them in 2016/17?
  - Emotional and psychological support for children and their families (yes/no)?
  - Bereavement care - to families *before* a child under the age of 1 has died (yes/no)?
  - Bereavement care - to families *after* a child under the age of 1 has died (yes/no)?
  - Bereavement care - to families *before* a child or young person aged 1 – 25 has died (yes/no)?
  - Bereavement care - to families *after* a child or young person aged 1 – 25 has died (yes/no)?
  - Equipment (yes/no)?

9. Do you commission any of the following services to provide care out of hours and at weekends for children with life-limiting or life-threatening conditions? We define 'out of hours and at weekends' as 6:30pm - 8am on weekdays and all day on Saturdays, Sundays and Bank Holidays.

- Voluntary sector children's palliative care services (including children's hospice services) (yes/no)?
- Emotional and psychological support for children and their families (yes/no)?
- Bereavement care - to families *before* a child under the age of 1 has died (yes/no)?
- Bereavement care - to families *after* a child under the age of 1 has died (yes/no)?
- Bereavement care - to families *before* a child or young person aged 1 – 25 has died (yes/no)?
- Bereavement care - to families *after* a child or young person aged 1 – 25 has died (yes/no)?
- Equipment (yes/no)?

### **Appendix three: Our methodology**

The figures quoted in our analysis calculated from the responses that Together for Short Lives received to freedom of information requests sent to all 152 upper-tier local authorities and all 207 clinical commissioning groups in June 2017. We sent reminder emails to those that did not respond and follow-up emails to those that provided incomplete information. You can view the questions that 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](#).

In total, 197 (93%) CCGs and 126 (83%) local authorities provided some or all of the answers to our questions. 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 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 **Monday 9 October 2017**.

## **Appendix four: What is commissioning?**

NHS England states<sup>30</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. It encompasses:

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

---

<sup>30</sup> NHS England (2016). NHS Commissioning. Available at: <http://bit.ly/2zADsNd>



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

**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>31</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>31</sup> Preparing for Adulthood (2015). Joint Commissioning in action. Available at: <http://bit.ly/1du8oSU>

