November 2014

NHS England: developing a new approach to palliative care funding: a first draft for discussion

A response from Together for Short Lives

Key messages

- We continue to support the principle of a per-patient funding system for children's palliative care to provide more sustainable and transparent funding - and NHS England's work to develop it. The currency is a helpful step forward in this process.

- The government and NHS England should provide guidance and allocate funding to make sure that those elements of children's palliative care outside of the scope of the new per-patient funding system are funded by clinical commissioning groups (CCGs) and local authorities; specifically, these include short break care not included in the currency and bereavement care.

- The government and NHS England should take action to make sure that the three separate sources of statutory funding for children's palliative care correlate with each other; these are specialised children's palliative care commissioning (from NHS England); general children's palliative care commissioning (from CCGs, through the per-patient system); and social care (from local authorities).

- There are a number of barriers to the success of the currency - including the potential costs to voluntary sector providers of implementing systems needed to gather data which they are not already collecting; the children's palliative care sector will need significant support to overcome these barriers.

Our aspirations for the new per-patient funding system

Our measures of success for new system are as follows:

1. Every baby, child and young person with a life-limiting or life-threatening condition - and their family - has access to palliative care services, which are sustainable and fairly funded.

2. The new system reimburses providers of children's palliative care according to the activity they undertake.

3. CCG commissioning of the general clinical aspects of children's palliative care through an NHS currency - and subsequently any tariff - complements NHS England's commissioning of specialised children's palliative care and local authorities' commissioning of the social elements of children's palliative care; together, this should create an overarching system whereby providers are commissioned for providing all of the elements of children's palliative care - including the clinical and non-clinical aspects of short breaks (respite) and bereavement care.

4. The system provides a clear incentive for both commissioners and providers to make sure that palliative care is provided in a child's home, in the community or in children's hospice settings - if this is consistent with the child or their family's preferences and is clinically appropriate.

We believe that it is not yet possible to say whether the new per-patient system will meet these criteria. We call on the government and NHS England to clarify a number of key issues as soon as possible.

We make our submission in two sections:

1. Our views on the draft currency.

2. Our views on wider statutory funding and commissioning for children's palliative care in England.

Section one: our position on the draft currency

The extent to which the currency is clinically meaningful

Broadly, we regard the draft currency as clinically meaningful. Some in the children's palliative care sector ask for NHS England to make it clearer as to why physical severity is a determinant of currency unit for community services but not hospice nor acute settings.

Factors that the draft currency does not take into account

The currency does not take into account the costs which children's palliative care providers will incur during the transition to the new per-patient system. This is in terms of the costs of setting up systems to record activity and the ongoing costs of collecting the data items. The Palliative Care Funding Review stated that introducing and implementing a funding system should be cost neutral to the sector. On this basis, providers should be reimbursed through the new system for these costs.

Opportunities in using the currency in local areas

We believe that the draft currency will provide an opportunity for CCGs to:

- better understand what the specific needs of children with life-limiting conditions are

- better understand what children's palliative care is and what the potential cost drivers are for commissioning

It is also an opportunity for commissioners and providers to initiate conversations about funding children's palliative care. It could lead to providers being reimbursed for caring for children and young people across a range of needs, including those which are the most complex.

Using the currency during a young person's transition from children's to adults' services

In defining age bands for children and young people in the currency, there is an opportunity to recognise the additional costs incurred by children's and adult's services of:

- planning for a young person's transition to adulthood in a timely way, beginning by the age of 14

- ensuring a smooth transition

- providing palliative care in settings which are appropriate to the young person’s age.

It is imperative that the new per-patient funding system promotes these principles. We recommend that the age. The Palliative Care Funding Review recommends that age cut-offs between the adult and children’s classification systems should be used in a flexible way, to best suit the needs of the patient.

We recommend that NHS England takes a similar approach to that of the Children and Adolescent Mental Health Services (CAMHS) Payment By Results Pilot Project. This has committed to helping ensure appropriate and smooth transitions between CAMHS and adult mental health services (AMHS). In doing so, the project has anticipated that its assessment and clustering model will apply to those clinical services that input to adolescent or adult transitional services. If specialist services consider that their population would be more appropriately served by the use of AMH clusters, the service will be able to decide - with their commissioners - which clustering framework makes most sense.

In supporting CCGs to implement the system, NHS England should emphasise how important it is to make sure that there are no gaps between children’s and adult’s palliative care services. For example, CCGs should ensure that there is no gap in local community nursing for individuals between the ages of 16 and 18. It is important that this currency does not lead to situations in which statutory funding for palliative providers caring for young person changes suddenly when they reach their 18th birthday - and/or when they transition from the children’s to the adult’s currency takes place. The transition to adult services is rarely on the young person’s 16th or 18th birthday - it may happen over a period time if and when it is appropriate for the transition to be made.

Recommendations for good transition planning for children with complex needs are set out in the report of CQC’s recent thematic inspection entitled “From the pond into the sea: children’s transition to adult health services”[1].

The barriers to implementing the currency

CCGs will not be obliged to use it

We are concerned that the draft currency will not end local variation in commissioning and funding of children’s palliative care on the basis that CCGs will not be obliged to use it.

Variation in the way it is interpreted and implemented

The currency may also be interpreted differently across CCGs and provider types. For example, a children's hospice may not consider the phase or physical severity associated with a fitting child to be changing. An acute hospital may view this situation differently.

It may also be difficult to ensure a consistent approach to determining when a child or young person is moving from the deteriorating to the dying phase. Estimates of time before death for children are particularly unreliable.

Unwillingness to disrupt current arrangements

There is a risk that voluntary sector providers of children’s palliative care which are receiving fair and sustainable statutory funding through existing arrangements will not encourage their

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[1] Care Quality Commission. 2014. From the pond into the sea: children’s transition to adult health services. Available online at: http://bit.ly/1uKT4Yf

commissioners to use the currency. This will be on the basis that it might lead to a reduction in funding.

Commissioners find it challenging to disaggregate historical funding agreements between CCGs and voluntary sector providers. CCGs may therefore be unwilling to divert resources to re-examine grants or contracts to align them with the new currency.

A lack of economies of scale

The relatively small number of children with life-limiting conditions within local areas - and the fact that most local areas do not reflect demand for children's palliative care in JSNAs - may not provide adequate incentives for CCGs to commission these services where they are not doing do already.

Costs of using the currency

Voluntary sector providers of children's palliative care use a range of systems for collecting data. The costs which children's palliative care providers will incur in setting up systems to gather data which they are not already collecting should not be greater the commissioned funding which they are likely to receive. Where this does occur, providers will be unlikely to engage with the currency. Providers will need support and advice to help them adapt to the new system.

Lead provider models

Some CCGs bundle commissioning of children's palliative care with other services. Voluntary sector providers can therefore rely on lead providers sub-contracting the dedicated packages of care which smaller organisations can provide. Lead providers are not obliged to do this. Where this model is in place, the currency may have little impact in securing fair and sustainable funding for children's palliative care providers.

VAT

At present, if a voluntary sector organisation is funded by grants and/or block contracts in addition to its core donation-based funding, any new hospice building or annex it constructs may be zero-rated for VAT. This is subject to any non-care areas being a de minimis proportion of the total. However, introduction of a tariff-based funding system, or enforced use of the NHS standard contract, has the unintended consequence that under current VAT legislation, the new hospice building or annex would have to be standard rated for VAT rather than zero rated. This is because HMRC views such funding as creating a business activity for the hospice's activities, rather than these being an exempt delivery of care, as is the case for grant-funded hospice services.

For this reason, a hospice may prefer to negotiate grant funding from CCGs rather than accepting the NHS standard contract.

The support that will be needed by commissioners and providers to implement the currency

- Commissioners and providers need to be reassured that the barriers set out above can be overcome.

- Voluntary sector providers will need funding and advice to help them implement the systems they will need in order to achieve funding through the draft currency.

- NHS England could usefully provide examples of how the currency will work when providing care for children and young people with continuing care packages and personal budgets (across education, health and care, as introduced by the Children and Families Act 2014).

- Providers would welcome further guidance on recording the start and end of a phase consistently in community settings. Case studies of children and young people in different phases and settings would be helpful; for example, if a child is staying in a children's hospice as part of a planned respite stay but has a change in phase during that stay, how would the currency support this in practice.

- Guidance should be provided on the skills required to decide when a phase has changed; we recommend that these decisions should be made by a range of health and social care professionals, not just medical doctors.

- NHS England could usefully provide template forms inputting data; training materials; and briefing presentations for trustees and senior managers within provider organisations.

- As part of guidance to CCGs, NHS England should emphasise that they are still able to grant to voluntary sector providers of children's palliative care.

- NHS England should describe how data quality be monitored.

We recognise that the following issues have considered by the Palliative Care Funding Programme team; however, on the basis that there is still uncertainty within the children's palliative care sector about the rationale or status of some elements of children's palliative care within the currency, we ask that NHS England works with us to help make clear whether providing telephone advice to professionals is included in the currency. We also ask that NHS England clearly describes why the currency does not include phases for babies under the age of one.

How the currency should be developed further in 2015/16

Together for Short Lives believe that the new system must encourage commissioners and providers to make sure that palliative care is provided in a child's home, in the community or in children's hospice settings - if this is consistent with the child or their family's preferences and is clinically appropriate. Page 10 of the Palliative Care Funding Review report states the new system should avoid increasing the number of people dying in hospital and provide an incentive to develop community services - providing better value for the taxpayer and better care for patients. We are concerned that in its present form, the draft currency will not do this.

The currency should not act as 'top-up' for acute sector providers, which are potentially able to access other tariffs to fund care for children with life-limiting conditions which voluntary sector providers cannot access. The government and NHS England should avoid a 'one size fits all' approach for all providers. Any pricing system which is developed should reflect the additional costs that the NHS will incur in maintaining care settings or in supplying general staff. It would be unfair, for example, if a tariff reflected the costs of care for non-hospital providers, including 'hotel' costs and all nursing and care staff - but not the 'general' care costs in hospitals - including the 'hotel' costs and general nursing and medical costs. We are keen that any tariff reflects the additional costs that the NHS will incur in maintaining care settings or in supplying general staff.

We believe that the currency should be developed in the following additional ways:

- We welcome plans to develop an England-wide dataset for children's palliative care. This will be crucial in further developing the currency and any subsequent payment system thereafter. Published data[2] shows that there are approximately 40,000 children and young people in England with life-limiting and life-threatening conditions. We ask that the currency is developed further as more data becomes available about future needs - and as this population changes.

- If a tariff is established, NHS England and Monitor should consider how it could be used to reward quality, for example through a best practice tariff; we draw NHS England's attention to the CQC's references to children's palliative care in its new regulatory regime - and the NICE clinical guideline on end of life care for infants, children and young people which is currently being developed - which could provide the basis for national quality markers.

- We call for more analytical work to be carried out to compare models of care and outcomes for families.

- We ask that the early implementers are requested to collect data on physical severity of children and young people's conditions across acute, hospice and community settings; this will help to provide further evidence about the extent to which severity influences activity in these settings.

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[2] Fraser LK, Parslow RC, McKinney PA, Miller M, Aldridge JM, Hain R, Norman P (2012) Life-limiting and life-threatening conditions in children and young people in the United Kingdom; final report for Together for Short Lives.

Section two: our position on wider statutory funding and commissioning for children’s palliative care in England

Sustainability

Providers of children’s palliative care are extremely uncertain about the future of the sources of statutory funding which they currently rely on. The government and NHS England must provide a policy framework which offers fair and sustainable funding for services.

The NHS England Children’s Hospice Grant

In addition to the uncertainty associated with the new, non-mandatory currency which is planned for March 2015, NHS England has yet to commit to continuing the children’s hospice grant during 2015/16 or beyond.

In January 2014, Together for Short Lives surveyed children's hospice organisations’ progress in developing relationships with health and social services commissioners in England and accessing statutory funding. We found:

- almost all (96%) of children’s hospice organisations thought that it would be unlikely that funding from CCGs would be at a level to replace their existing NHS England grant funding by the end of March 2014; on average, the NHS England grant covered 13% of the care costs incurred by children’s hospices in 2013/14

- 89% of children’s hospice organisations may be forced to reduce their services if the NHS England grant stopped; nearly two-thirds (62%) would reduce short break services, a third (35%) would reduce family support and nearly a quarter (23%) would reduce the amount of end of life care they provide.

Funding from CCGs

CCG funding for children’s palliative care is currently inconsistent. We are concerned that this pattern will continue under the new system.

Funding from CCGs continues to represent a relatively modest proportion of children’s hospice organisations’ total income and the overall costs of delivering care. Our survey of children’s hospices’ statutory funding found that, on average, local CCG funding contributed 12% to the cost of care provided by children’s hospices. This is also inconsistent: over a third of CCG funding across England supports just two children’s hospice organisations.

Maintaining statutory funding in the transition to the new system

‘Developing a New Approach to Palliative Care Funding’ only partly addresses the issue of fairness and sustainability. It is crucial that the overall level of statutory funding for children’s palliative care providers does not fall as the new system is introduced. The government and NHS England now provide the clarity which providers need as soon as possible. **This includes committing to continue the Children’s Hospice Grant during the transition to the new system.**

Without this, children’s palliative care services will be unable to plan with confidence. Many may be forced to reduce services if they are unable to accurately forecast how much commissioned or granted funding they are likely to receive.

The scope of the new system

Together for Short Lives is concerned that the elements of children's palliative care which lie outside the scope of the proposed currency will not receive fair and sustainable statutory funding without government action.

It is crucial that any new system does not exclusively promote a narrow, clinical model which focuses only on the child. Palliative care for children with a life-limiting or life-threatening condition is 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 enhancing quality of life for the child or young person. It also supports the family. It includes managing distressing symptoms, providing short breaks and care through death and bereavement.

This holistic model of children's palliative care is reflected in national policy documents which have been developed by statutory bodies in England. In 'Actions for End of Life Care: 2014-16'[3], NHS England recognises that "to improve end of life care for all...actions are required across the system, including in social care, public health and education. The Care Quality Commission's recent handbook sets out the key lines of enquiry which will be used in inspecting children's hospices[4]. This states that in outstanding providers "bereavement services are tailored to individual needs and may be provided over a significant period of time after death." Inspectors are encouraged to find out the extent to which a "service make(s) sure that people, and those that matter to them, have available, as appropriate, the emotional, spiritual/religious and bereavement support they want, before, during and after death." The recent National Institute for Health and Care Excellence (NICE) draft scope for the clinical guideline on 'End of Life Care for Infants, Children and Young People'[5] recognises that children's palliative care includes providing psychological, social and spiritual support for infants, children and young people with an incurable condition - and their family members or carers (as appropriate).

Short breaks

We welcome the fact that short breaks comprising planned in-patient and/or community care (for example, to monitor the clinical needs of a child and to make any necessary adjustments to their care) are included within the scope of the draft currency.

However, we are concerned that, at present, short breaks which provide respite for carers and families of children and young people who need palliative care are outside of the scope of the pilot. We note that the Palliative Care Funding Review recommended on page 59 of its report that:

> "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."

Together for Short Lives' surveys of children's hospices' statutory funding in England have shown that this is not happening. Despite being key providers of short breaks for children and young people with life-limiting and life-threatening conditions and their families, a third of children's hospices are not recognised by their local authorities as being providers. 42% of children's hospice organisations receive no funding at all from their local authorities.

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[3] NHS England. 2014. Actions for End of Life Care: 2014-16. Available to download at: http://bit.ly/1F4TX0C

[4] Care Quality Commission. 2014. How CQC regulates: adult social care: hospice services: appendices to the provider handbook. Available to download at: http://bit.ly/1p1yWjq

[5] National Institute for Health and Care Excellence. 2014. Clinical guideline scope: end of life care for infants, children and young people. Available to download at: http://bit.ly/1zDV1Wm

Where they are recognised, only 2.4% of the average annual cost of care provided by children's hospices is funded by local authorities. This has been a trend over the last five years, with local authority support remaining broadly static and representing a small part of services' commissioned income.

It is also important that young adults with life-limiting conditions are able to access short breaks following their transition to adult services. We note that short breaks for adults have not been addressed by the pilot. Many young adults and their families continue to need short breaks, which in many cases will require greater clinical input as young adults' conditions deteriorate over time. This includes short breaks for respite, monitoring clinical needs and adjusting their care.

We recognise that children's social care is free at the point of use, while adult social care may be funded by local authorities, individuals or other means. We also recognise that local authorities are obliged to provide a range of short breaks for disabled children and young people. They are obliged to take action to prevent, reduce or delay needs in adults. The latter can include respite, but this isn't specified in the Care Act itself, only suggested in the statutory guidance.

However, given the clinical support that young adults could require during a short break, we believe that these services should receive fair and sustainable statutory funding.

Bereavement

Page 56 of the Palliative Care Funding Review report states that "pre-bereavement support is an absolutely essential part of palliative care and should be fully funded by the state." We welcome the fact that the pilot programme has collected data on pre-bereavement support.

However, we also note that the review stated that state-funded bereavement support for carers of young people with life-limiting conditions who die is crucial. The review cited evidence which demonstrated that services for bereaved children are not universal, with only 65-70% of local authority areas having an 'open access' service available to any bereaved child in their area.

Funding and guidance

We are concerned that without government action, these crucial elements of children's palliative care which are not within the scope of the per-patient system will simply continue to be overlooked. Local authorities - which are under significant pressure to make cost-savings - are highly unlikely to make new resources available to fund these services.

Therefore, to accompany NHS England's draft currency for children's palliative care being published, **Together for Short Lives calls for the government to issue local authorities in England with a statutory guide on how to commission short breaks and bereavement care for carers and families or children and young people who need palliative care - and provide them with dedicated funding to enable them do so.**

We ask the government to use Together for Short Lives' published guidance for local authorities[6] as the basis for such a guide.

Integrating palliative care funding and commissioning

When the new system is in place, the children's palliative care sector in England should receive commissioned funding from three separate sources:

- NHS England, which should commission specialised children's palliative care consistent with its own service specification Eh3[7].
- CCGs, which should commission general children's palliative care use the new per-patient funding system.
- local authorities, which should commission the social elements of children's palliative care (such as short breaks and bereavement care for siblings and families).

It is vital that all three sources complement each other. At present, we believe there is a real danger that local areas will regard those services included within the per-patient funding system as the entity of children's palliative care - and continue to fail to fund those elements which are out of scope. Together for Short Lives also remains concerned that NHS England's specialised children's palliative care specification does not make clear the differences between specialised and general palliative care. In publishing the new per-patient funding system, we call upon the government and NHS England to provide a guide to CCGs to provide clarity over what constitutes specialised and general palliative care - and make clear that CCGs are responsible for commissioning the latter.

Guidance should also emphasise the Children and Families Act 2014, which places a duty on the NHS and local authorities to jointly commission care for children and young people with special educational needs and disabilities (SEND) between the ages of 0 – 25. This includes palliative care. Guidance should also reference section 75 of the National Health Services Act 2006 which allows NHS bodies and local authorities to pool budgets locally.

The SEND Code of Practice[8] recommends that Health and Wellbeing Boards consider the needs of children and young people who need palliative care. Children's palliative care should, therefore, be included within Joint Strategic Needs Assessments and Joint Health and Wellbeing Strategies. This should provide a basis for NHS England, CCGs and local authorities to collaborate in commissioning children's palliative care.

Disappointingly, in our 2014 children's hospice funding survey, a significant proportion of children's hospice organisations (38%) report that children's palliative care has not been included in their Joint Strategic Needs Assessment (JSNA).

Together for Short Lives' published guide for CCGs[9] refers to the policy drivers above and could provide the basis for this advice to commissioners.

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[6] Together for Short Lives (2014). Children's palliative care: a guide for local authorities. Available to download from: http://bit.ly/1A7K5AM

[7] 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

[8] Department for Education (2014): Special educational needs and disability code of practice: 0 to 25 years: Statutory guidance for organisations who work with and support children and young people with special educational needs and disabilities: July 2014. Available to download from: http://bit.ly/1ri6Nkm

[9] Together for Short Lives (2014). Children's palliative care: a guide for clinical commissioning groups. Available to download from: http://bit.ly/1opjNHx

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