

25 January 2013

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**Cc:**

Dr Martin McShane, Director for Domain 2  
Barbara Howe, Lead Commissioner for Specialised Paediatric Palliative Care Services  
Dr Jacqueline M Cornish, OBE, FRCP, Chair, Women and Children, Congenital and Inherited Diseases Programme of Care and the Paediatric Medicine Clinical Reference Group

Dear James

**Specialised services commissioning consultation  
Service specification E3h: Paediatric Palliative Care**

We welcome the opportunity to comment on the NHS Commissioning Board's (NHSCB) consultation on specialised services commissioning. We have come together as umbrella bodies and organisations spanning both children's and adult's palliative care to respond to the specification for specialist paediatric palliative care.

We welcome the NHSCB's proposal to classify certain elements of paediatric palliative care as a specialised service. However, we feel that the specification should be developed further in order to ensure clear lines of accountability and alignment between the commissioning of childrens and adults palliative care.

Our response includes three key concerns:

1. Transition: commissioning care for young people moving from children's to adult services.
2. The division of commissioning responsibilities between the NHSCB and Clinical Commissioning Groups (CCGs).
3. The timescale for responding to this consultation.

**1. Transition**

The interface between paediatric and adult palliative care services, and young adults' transition between them, requires careful consideration. Many young people and families currently find that their transition from children's to adult services is marred by a lack of communication between local providers and a struggle to secure the care they need. By making the specialised service specification clearer, NHSCB has an opportunity to better align children's and adult services nationally and locally for the benefit of young adults with palliative care needs.

The introduction to the service specification on page one highlights the numbers of children and young people who require palliative care today. It should also refer to the increasing

number of such young people who are living into adulthood and are transitioning to adult services.

We welcome the statement on page four that all young adults should be helped to make end of life care plans. We do, however, urge caution over the proposal that this should happen when the end of life stage is recognised. Wherever possible and appropriate, young adults should be helped to think about their preferences *in advance of this stage* being reached. This is particularly important for young people because the trajectory of their condition may be difficult to predict - their 'end of life stage' is sometimes not recognised in time.

As they transition to adult services, young adults will come into contact with care teams who are new to them and their families. Teams will need time before having these difficult conversations, increasing the risk of plans not being in place should a young person deteriorate rapidly during or soon after transition. Specialised paediatric palliative care services therefore need to play a role in preparing young people and their families ahead of transition. NHSCB should make this clear in the specification - for example by making this explicit in the first two outcomes on page 11 by adding the point 'especially where transition to adult services is imminent' or similar.

We welcome the specification's acknowledgment on page 17 of the serious consequences that poorly planned transitions can have for young people. We ask that this point is made earlier on and alongside the document's brief mentions of transition pathways, including those on pages five, six and nine.

We are concerned that the current specialised service specification could exacerbate existing inequities in care where there are differing local arrangements for community nursing. The specification states that children with life limiting or life threatening conditions will have access to specialised paediatric palliative care up to the day before their 19<sup>th</sup> birthday. In some areas community children's nurses will only care for young people up to the age of 16. Where this is the case, care should transfer to district nurses. However, some nurses will not provide palliative care to young people aged 16 - 19 unless commissioned to do so by their Primary Care Trust (PCT) cluster and/or CCG.

NHSCB will be aware of the current review of palliative care funding and the Government's aspiration for a new tariff to be implemented by 2015. Ultimately, the finalised specialised service specification and the tariff together must, between them, cover all health aspects of children's palliative care. Failure to do so will be detrimental to efforts to bring about sustainable services for children, young people and families who need them. NHSCB should reference the review in this specification and update the document when the tariff is implemented.

NHSCB should carefully consider how commissioning at both specialist and CCG levels can facilitate smooth transitions for young people with palliative care needs. It should also ensure that children's access to paediatric palliative care services is portable across different local areas. NHSCB should monitor services to ensure that they do not become fragmented for young people in transition.

## **2. The division of commissioning responsibilities**

We strongly recommend further clarification on how commissioning responsibilities will be divided between NHSCB and Clinical Commissioning Groups (CCGs). As it stands, the specification is too ambiguous: NHSCB must ensure that the specialised services it commissions align with those commissioned by CCGs locally. Without clarity, vital elements of children's palliative care could remain unsupported and underfunded in some areas.

We recommend that appropriate guidance is produced for commissioners to ensure that this specialised specification is not regarded as a children's palliative care service in its entirety. In doing so, we ask NHSCB to identify the consultant activity codes which it will be using to identify what is described as specialised services.

### 3. Timescale

Finally, we wish to emphasise our concern at the amount of time allocated by NHSCB for responding to this consultation - and the time of year at which it has been held. This has made it virtually impossible to obtain the views of those using and providing palliative care services.

We call for more appropriate timescales in future, in addition to a more transparent and accountable process for formulating service specifications. Enabling greater opportunities for those whom we represent to shape this process can only improve palliative care services in the long-term.

We look forward to continuing to work constructively with NHSCB to develop a specialised commissioning specification that ensures children, young adults in transition and their families receive the care they need - and puts the services which provide them on a sustainable financial footing.

Yours sincerely

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