



NEL,  
1 Lower Marsh,  
London,  
SE1 7NT

Email: [NELCSU.foi@nhs.net](mailto:NELCSU.foi@nhs.net)

Dear Mr Steer

**Re: Freedom of Information request**

Reference: FOI.20.SHS200

10 March 2021

Thank you for your request under the *Freedom of Information Act 2000* (the Act). This response is provided on behalf of NHS Surrey Heartlands Clinical Commissioning Group (CCG). Your request along with the CCG's response is detailed below.

- 1. Do you have a children's palliative care service specification? (Yes/No). If so, please attach a copy to your response to this request.**

Yes. Please find the attached service specification, Annex A.

- 2. Do you have a children's palliative care service specification which states that infants, children and young people with a life-limiting condition and their parents or carers should have opportunities to be involved in developing an advance care plan? (Yes/No)**

No. This is not stated in the service specification at this time with clear involvement for parents or carers. The below excerpt from the service specification suggests that this would be possible.

"I can work with my team to agree a care and support plan (this can be an Advance Care Plan as per NICE NG61). My care plan is entered on my record and is available to all who need to read it".

- 3. Do you have a children's palliative care service specification which states that infants, children and young people with a life-limiting condition should have a named medical specialist who leads and coordinates their care? (Yes/No)**

Yes.

"Communication: Establishment of a regular core Specialist PPC MDT will ensure a holistic approach to care."

"APC: Specialist PPC will support and lead on Advance care planning (including ReSPECT and Co-ordinate My Care) from implementation, education, clinical support and review."

- 4. Do you have a children's palliative care service specification which states that infants, children and young people with a life-limiting condition and their parents or carers should be given information about emotional and psychological support, including how to access it? (Yes/No)**

Yes. The specialist core palliative care team will provide the operational delivery as the "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)".

- 5. Do you have a children's palliative care service specification which states that infants, children and young people with a life-limiting condition should be cared for by a multidisciplinary team that includes members of the specialist paediatric palliative care team? (Yes/No)**

Yes.

"MDT interdependency services - including PICU and tertiary NICU".

"a specialist paediatric MDT team which will include, 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)".

- 6. Do you have a children's palliative care service specification which states that parents or carers of infants, children and young people approaching the end of life should be offered support for grief and loss when their child is nearing the end of their life and after their death? (Yes/No)**

Yes. The key components of the specialist palliative care team includes;

- Psycho-social support for children, young people, families and professionals.
- Bereavement support.

7. Do you have a children's palliative care service specification which states that infants, children and young people 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 paediatric palliative care? (Yes/No)

"The team requires expansion to meet the NICE core MDT model. The team has access to a multitude of experts in child and family support via the hospice service. An additional consultant post will support NICE guidance on the availability of a consultant in a paediatric palliative care available 24.7".

8. Do you have a children's palliative care service specification which states that infants, children and young people with a life-limiting condition and their families should have access regular short breaks for respite? (Yes/No)

No.

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If you remain dissatisfied, you can ask us to review our decision by making a written request for an internal review. In order to assist with the review, you should include your address, a description of the original request and the reasons why you are dissatisfied. Please send this to:

#### Email

[NELCSU.foi@nhs.net](mailto:NELCSU.foi@nhs.net)

#### Postal address

NEL CSU,  
1 Lower Marsh,  
London,  
SE1 7NT

#### Website address

[www.nelcsu.nhs.uk](http://www.nelcsu.nhs.uk)

The review will be handled by more senior staff who were not involved in the original decision. Although this will not apply to Section 36 claimed exemptions in accordance with Department of Health Directive, your request will still be reviewed. We aim to complete all internal reviews within 20 working days. If you then wish to appeal you should contact the Information Commissioner for an independent review at the following address:

#### Telephone

0303 123 1113

#### Postal address

The Information Commissioner,  
Wycliffe House,  
Water Lane,  
Wilmslow,  
Cheshire,  
SK9 5AF

#### Website address

[www.ico.org.uk](http://www.ico.org.uk)

### Feedback

Your feedback is welcome to help us improve the service we provide. Please send comments or suggestions to our address.



Yours sincerely

**Freedom of Information Team**

NEL