

Dan Steer
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Date: 24th February 2021
Ref: 21-023

Dear Dan,

RE: Freedom of Information request

I am writing in response to your e-mail received on the 15th February 2021 for information held by NHS Leeds CCG (“CCG”) under the provisions of the Freedom of Information Act 2000 (“the Act) and on behalf of the CCG. For ease of reference your query has been reproduced below along with our response.

Query:

The questions below which we would like you to answer are designed to help me understand how you commission children’s palliative care for children and young people with life-limiting and life-threatening conditions in your local area. In order to help you meet my request, I provide definitions to the terms I use in my questions below:

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.”

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.”

Please note that NHS England and NHS Improvement has created a draft Children’s and Young People’s Palliative and End of Life Care Service Specification. This is available for CCGs to access from the [FutureNHS Collaboration Platform](#)

The following national standards apply to palliative and end of life care for children and young people in England:

NICE Guidance NG 61: End of life care for infants, children and young people with life-limiting conditions: planning and management
<https://www.nice.org.uk/guidance/ng61>

NICE Quality Standard QS 160: 2017. End of life care for infants, children and young people – NICE quality standard [QS160].
<https://www.nice.org.uk/guidance/qs160>

Department of Health. 2016. ‘Our Commitment to you for end of life care: The Government Response to the Review of Choice’.
<http://bit.ly/2oOUsfj>

NICE guideline NG43: 2016. Transition from children to adults’ services for young people using health or social care services
<https://www.nice.org.uk/guidance/ng43>

NICE Quality standard QS140: 2016. Transition from children to adults’ services
<https://www.nice.org.uk/guidance/qs140>

My questions

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.
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)

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)
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)
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)
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)
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)
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)

Response:

NHS Leeds CCG does not have a children's palliative care specification, but Children's Palliative Care Nursing sits within the wider specification for Children's Community Nursing, which includes life limiting and life-threatening illness management, including palliative and End of Life care. This specification does not outline the service delivery in the detail outlined in the questions.

I would like to draw your attention to the provisions of the Re-use of Public Sector Information Regulations 2005. I should point out that the information we have supplied is the property of the CCG and subject to Intellectual Property and



Database Rights. Any commercial application or use of this information may be subject to the provisions of the above Regulations. This means that if you wished to re-use any of the information provided for commercial purposes you would need to ask us for permission to do so. Should we agree that you can use the information it will be subject to the issue of a licence which may or may not involve a fee.

If for any reason you are unhappy with the service you have received in relation to your request, you have a right to appeal to an independent officer within NHS Leeds CCG. They will re-examine your request and assess whether we have adhered to the requirements of the act. Should you wish to follow this course of action please address your concerns in writing to the above address.

If you continue to be dissatisfied, you have the right to contact the Information Commissioner. Generally, the Commissioner cannot make a decision until you have exhausted the CCG's complaints procedure. Should you wish to contact the Information Commissioner, you can do by writing to The Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF.

Yours sincerely



Leonardo Tantari
Chief Digital and Information Officer, Senior Information Risk Officer (SIRO)

