



North East and North Cumbria

Our Reference SD\North East and North
Cumbria ICB\FOI ICB637

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13 December 2023

Dear

Freedom of Information Act 2000 – Request for Information – NHS North East and North Cumbria Integrated Care Board (NENC ICB)

Thank you for your request received by North of England Commissioning Support (NECS) on 23 November 2023 for information held by NHS North East and North Cumbria Integrated Care Board (NENC ICB) under the provisions of the Freedom of Information Act 2000.

NENC ICB covers the areas of County Durham, Gateshead, Newcastle, North Cumbria, North Tyneside, Northumberland, South Tyneside, Sunderland, and Tees Valley (which covers the 5 councils that make it up – Darlington, Hartlepool, Middlesbrough, Redcar & Cleveland, and Stockton-on-Tees).

Please find the information you requested on behalf of the ICB as follows.

Your Request

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 ICB footprint. 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 has created a draft Children’s and Young People’s Palliative and End of Life Care Service Specification. [This is available for ICBs to access here from the NHS England website.](#)

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

Ambitions for Palliative and End of Life Care. Available to download from: <https://www.england.nhs.uk/publication/ambitions-for-palliative-and-end-of-life-care-a-national-framework-for-local-action-2021-2026/>

Palliative and end of life care: statutory guidance for integrated care boards (ICBs): <https://www.england.nhs.uk/publication/palliative-and-end-of-life-care-statutory-guidance-for-integrated-care-boards-icbs/>

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>

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. Has your ICB completed an Ambitions for Palliative and End of Life Care self-assessment? (Yes/No). If yes, please attach your completed self-assessment to your response to this FOI request.
3. 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)
4. 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)

5. Do you have a children's palliative care service specification which states that infants, children and young people with a life-limiting condition, their parents or carers and their siblings should be given information about emotional and psychological support, including how to access it? (Yes/No)
6. 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)
7. Do you have a children's palliative care service specification which states that siblings and 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)
8. 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)
9. 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)

Our Response

The North East and North Cumbria Integrated Care Board (NENC ICB) does hold the records which you have sought around children's palliative care for children and young people.

The responses to question 1 and questions 3-9 were made publicly available in our response to FOI request ICB412. This can be sourced in the Disclosure Logs on the NENC ICB website, using the link <https://northeastnorthcumbria.nhs.uk/about-us/publications/disclosure-log/>

For question 2, North East and North Cumbria ICB does not currently hold this information. In North Cumbria place, the self-assessment has not yet started. For the North East places, work on this is on-going with the aim of completing in the New Year. This information should be ready in April 2024 and will be reassessed at that point.

In addition, **County Durham** have begun the process to complete the Adults PEOL Care Self-Assessment as part of the County Durham PEOL Care Steering Group's agenda. However, at this stage, this is an adult only forum. A discussion at the next regional PEOL Care Commissioner's Forum is planned for January 2024 and we will be seeking a steer on whether locality PEOL Care forums are to include children. A self-assessment for children's PEOL Care is likely to follow that.

For question 9 at **Gateshead** place, this is commissioned by Gateshead LA for children's services and NENC ICB are associates.

In **Northumberland**, in response to question 9, Northumberland County Council is the lead organisation, but the service is co-funded by NENC ICB.

For **South Tyneside** place, South Tyneside LA are lead commissioner on behalf of the LA's and NENC ICB are associates that utilise the service under those contractual terms and conditions.

As such, the North East and North Cumbria Integrated Care Board does not hold all the records which you have sought. However, we have determined that some of the requested information is held by Local Authorities within the North East and North Cumbria region.

In accordance with our duty under s.16 of the FOIA to provide reasonable advice and assistance to an individual requesting information, we have provided the FOI email addresses for the NENC region Local Authorities to make your request.

NENC Local Authorities	Email
Cumbria County Council	information.governance@cumbria.gov
Darlington Borough Council	freedomofinformation@darlington.gov.uk
Durham County Council	foi@durham.gov.uk
Gateshead Council	informationrights@gateshead.gov.uk
Hartlepool Borough Council	freedomofinformation@hartlepool.gov.uk
Middlesbrough Borough Council	foi@middlesbrough.gov.uk
Newcastle City Council	freedomofinformation@newcastle.gov.uk
North Tyneside Council	foiofficer@northtyneside.gov.uk
Northumberland County Council	foi@northumberland.gov.uk
Redcar & Cleveland Borough Council	information_security@redcar-cleveland.gov.uk
South Tyneside Council	foi@southtyneside.gov.uk
Stockton on Tees Borough Council	foiandcomplaints@stockton.gov.uk
Sunderland City Council	freedom.information@sunderland.gov.uk

In line with the Information Commissioner's directive on the disclosure of information under the Freedom of Information Act 2000 your request will form part of our disclosure log. Therefore, a version of our response which will protect your anonymity will be posted on the NHS ICB website <https://northeastnorthcumbria.nhs.uk/>.

If you have any queries or wish to discuss the information supplied, please do not hesitate to contact me on the above telephone number or at the above address.

If you are unhappy with the service you have received in relation to your request and wish to make a complaint or request a review of our decision, you should write to the Senior Governance Manager using the contact details at the top of this letter quoting the appropriate reference number.

If you are not content with the outcome your complaint, you may apply directly to the Information Commissioner for a decision. Generally, the Information Commissioner cannot make a decision unless you have exhausted the complaints procedure provided by the North of England Commissioning Support Unit.

The Information Commissioner can be contacted at:

Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF

www.ico.org.uk

Any information we provide following your request under the Freedom of Information Act will not confer an automatic right for you to re-use that information, for example to publish it. If you wish to re-use the information that we provide and you do not specify this in your initial application for information then you must make a further request for its re-use as per the Re-Use of Public Sector Information Regulations 2015 www.legislation.gov.uk . This will not affect your initial information request.

Yours sincerely

S Davies

S Davies
Information Governance Officer