

Our Reference North East and North Cumbria ICB\
FOI ICB 24–283

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By Email

6 November 2024

Dear Applicant

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 11 October 2024 for information held by NHS North East and North Cumbria Integrated Care Board (the ICB) under the provisions of the Freedom of Information Act 2000.

The ICB covers the areas of County Durham, Gateshead, Newcastle, North Cumbria, North Tyneside, Northumberland, South Tyneside, Sunderland, and Tees Valley (which covers the five local authorities of Darlington, Hartlepool, Middlesbrough, Redcar and Cleveland and Stockton-on-Tees).

We have dealt with your request in accordance with your “right to know” under section 1(1) of the Freedom of Information Act 2000 (subsequently referred to as FOIA2000) which entitles you to be provided with information “held” by a public authority unless an appropriate exemption applies.

Your Request

The questions below which we would like you to answer are designed to help me understand how **NHS North East and North Cumbria ICB** commissions children’s palliative care for children and young people with life-limiting and life-threatening conditions in its 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.](#)

We have also launched a new resource to help ICBs commission children’s palliative care. This resource can be accessed [here](#).

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)
 - a. *Note:* We would like to capture those areas where registered nurses can provide both core and specialist children's palliative care to children with a range of medical complexity. We acknowledge that, where this is provided, it is done so by nurses with different roles, employed by the NHS and/or the voluntary sector. This will include specialist children's palliative care nurses providing care directly or providing advice to other nurses providing direct care.
 - b. *Note:* NHS England state that specialist children's palliative care teams should be led by specialist medical consultants. These specialist consultants are vital because they:
 - i. Have specialist expertise in managing life-threatening illness and life-limiting conditions across the paediatric spectrum.
 - ii. The ability to manage the full range of symptoms experienced as disease and illness progresses.
 - iii. Lead and develop services within their region.
 - iv. Enable, support, teach and train other health care professionals.
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

We can confirm, as per Section 1(1) of the Freedom of Information Act 2000, the ICB holds some of the information you have requested. The information is not held in the North East ICB place, but North Cumbria place holds the information detailed below.

1. In North Cumbria, children are included in the specification from Eden Valley Hospice but this also includes adults. There is no specification for North Cumbria Integrated Care Hospitals NHS Foundation Trust (NCIC).
2. We cannot determine whether the ICB has completed an Ambitions for Palliative and End of Life Care self-assessment for North Cumbria ICB place.
3. Yes, in the specification for Eden Valley Hospice. NCIC support families with developing ACP, however this is under guidance of consultants as they need to sign it off.
4. This is not specified on service spec from Eden Valley Hospice and NCIC do not have a children's palliative care service spec.
5. Yes, included in the service spec for Eden Valley Hospice. NCIC do not have a palliative care service spec.
6. No. there is no such specification in North Cumbria place.
7. This is included on the service specification for Eden Valley Hospice but not in the service specification for NCIC.
8. No, unable to provide 24-hour care due to lack of resources.
9. No, respite is included in the service specification, but regularity is not specified and as previously mentioned the service spec is not specifically children.

In accordance 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 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 review, you do have the right of complaint to the Information Commissioner as established by section 50 of the Freedom of Information Act 2000. 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