

Our Reference North East and North Cumbria ICB\
FOI ICB 25–270

North East and North Cumbria ICB
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By Email

6 November 2025

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 on 8 October 2025 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, Newcastle Gateshead, North Cumbria, North Tyneside, Northumberland, South Tyneside, Sunderland, and Tees Valley.

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 us understand how NHS North East and North Cumbria ICB commissions palliative care for children and young people with life-limiting and life-threatening conditions in its ICB footprint. In order to help you meet our request, I provide definitions to the terms used 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. Does your ICB have a children's palliative care service specification? (Yes/No). If yes, 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 request.
3. In your local area, does your ICB commission services which ensure infants, children and young people with a life-limiting or life-threatening condition and their parents or carers have opportunities to be involved in developing an advance care plan? (Yes/No/Partially). If yes or partially, please provide supporting evidence such as a relevant service specification.

4. In your local area, does your ICB commission services which ensure infants, children and young people with a life-limiting or life-threatening condition have a [named medical specialist](#) who leads and coordinates their care? (Yes/No/Partially). If yes or partially, please provide supporting evidence such as a relevant service specification.
5. In your local area, does your ICB commission services which ensure infants, children and young people with a life-limiting or life-threatening condition, their parents or carers and their siblings are given information about emotional and psychological support, including how to access it? (Yes/No/Partially). If yes or partially, please provide supporting evidence such as a relevant service specification.
6. In your local area, does your ICB commission services which ensure infants, children and young people with a life-limiting or life-threatening condition are cared for by a multidisciplinary team that includes members of the [specialist paediatric palliative care team](#)? (Yes/No/Partially). If yes or partially, please provide supporting evidence such as a relevant service specification.
7. In your local area, does your ICB commission services which ensure siblings and parents or carers of infants, children and young people approaching the end of life are offered support for grief and loss when their child is nearing the end of their life and after their death? (Yes/No/Partially). If yes or partially, please provide supporting evidence such as a relevant service specification.
8. In your local area, does your ICB commission services which ensure infants, children and young people approaching the end of life and being cared for at home have [24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care](#)? (Yes/No/Partially). If yes or partially, please provide supporting evidence such as a relevant service specification.
 - 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. In your local area, does your ICB commission services which ensure infants, children and young people with a life-limiting or life-threatening condition and their families have access to regular short breaks for respite? (Yes/No/Partially). If yes or partially, please provide supporting evidence such as a relevant service specification.

Our Response

1. NENC ICB uses a national service specification. The specification defines the standards of care expected from organisations funded by NHS England to provide specialised care. The Children's Holistic Integrated Palliative Care Service (CHIPS) is a specialised service and defined by the National Specification. This is a NENC wide proviso for all children requiring palliative and end of life care. The specification is attached.

2. Yes, NENC ICB has completed an Ambitions for Palliative and End of Life Care self-assessment. The attached self-assessment was completed separately for both adults and children's services.
3. Yes, NENC ICB commissions services which ensure infants, children and young people with a life-limiting or life-threatening condition and their parents or carers have opportunities to be involved in developing an advance care plan.

The CHIPS Childrens Holistic Integrated Palliative care final updated document attached outlines support for advance care planning, including coordination and decision-making with families.

NENC advocate the use of the Deciding Right suite of documents to record advance care planning, and this is offered across all children's services supported by the CHIPS team and detailed in the National Service Specification.

4. Yes, NENC ICB commissions services which ensure infants, children and young people with a life-limiting or life-threatening condition have a named medical specialist who leads and coordinates their care. This is specified in the National Service Specification.

The CHIPS Childrens Holistic Integrated Palliative care final updated document attached confirms that care is coordinated by specialist paediatric palliative care teams, including named consultants.

5. Yes, NENC ICB commissions services which ensure infants, children and young people with a life-limiting or life-threatening condition, their parents or carers and their siblings are given information about emotional and psychological support, including how to access it. This is detailed in the national service specification.

Emotional and psychological support is embedded in the CHIPS service model and referenced in the Paediatric-Palliative-Care-Guidelines-CHIPS-GNCH-Sept-2022.

The attached NHS Commissioning and Investment Framework for PEO LC April22 and CHIPS Childrens Holistic Integrated Palliative care final updated detail MDT structures including consultants, nurses, psychologist and other specialists.

6. NENC ICB does commission services which ensure infants, children and young people with a life-limiting or life-threatening condition are cared for by a multidisciplinary team that includes members of the specialist paediatric palliative care team.

The National Service Specification, the NHS Commissioning and Investment Framework for PEO LC April22 and CHIPS Childrens Holistic Integrated Palliative care final updated detail MDT structures including consultants, nurses, and other specialists.

7. Yes, NENC ICB commissions services which ensure siblings and parents or carers of infants, children and young people approaching the end of life are offered support for grief and loss when their child is nearing the end of their life and after their death.

Bereavement support is included in the CHIPS model and referenced in the Stepping Up for young people, parents, carers and professionals attached.

8. NENC ICB partly commissions services which ensure infants, children and young people approaching the end of life and being cared for at home have 24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care.

The CHIPS Service are in the process of establishing a 24/7 service as per the Service Specifications. The attached document – Ref-586-NCMD-Palliative-and-End-of-Life-Care-report-FINAL-1 children – highlights gaps in 24-hour access in some areas, but efforts are underway to improve coverage. Community children services offer core palliative care with support from the specialist chips team across NENC

The Children and Young Persons Oncology Outreach Nurse Specialist (CYPOONS) services offer 24/7 support to children with cancer who are requiring palliative and end of life care.

9. Yes, NENC ICB commissions services which ensure infants, children and young people with a life-limiting or life-threatening condition and their families have access to regular short breaks for respite. Children's Hospices offer short respite breaks for families and children with complex life limiting conditions.

The Stepping Up for young people, parents, carers and professionals outlines short break services available across the region, including community-based and residential options.

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 Information 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 ICB's complaints procedure.

The Information Commissioner can be contacted at Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF or 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 faithfully

Information Governance Support Officer

**Information Governance Support Officer
North East and North Cumbria Integrated Care Board**