

11/07/2023

NN-ICB/23/335

Dear Requestor

RE: Freedom of Information Request

With reference to your request for information I can confirm in accordance with Section 1 (1) of the Freedom of Information Act 2000 that we do hold the information that you have requested. A response to each part of your request is below.

Please note that Integrated Care Boards (ICB) commission:

- Children's community nursing teams
- Specialist short break services/respice
- Routine care delivered by a children's hospice service that is not a Highly Specialist Paediatric Palliative Care Centre
- Carers and care packages
- Local, community-based palliative care services

The following answers are therefore only relating to the ICB elements.

In the request you asked:

- 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, the ICB has a children's palliative care service specification for the following;

- as part of the children's community nursing team element of the attached specification.
- for the ICB's commissioning of routine care delivered by a children's hospice.
- for support services.

Please see attached specifications.

- 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.

- 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)

No. This is commissioned by NHS England.

- 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. Please see attached specifications which all include provision of emotional and psychological support. However, it is not stated within these specifications as to how the access is provided.

- 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)

No, however multidisciplinary team care is included in the specifications but does not specifically state members of the specialist paediatric palliative care team.

- 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.

- 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)

Yes, for children's community nursing and for 24/7 medical advice under the hospice service specification from the hospice medical teams.

- 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 to regular short breaks for respite? (Yes/No)

Yes, for hospice care the specification includes 10 nights of specialist residential palliative respite care per child over a year.

No, not within the children's community nursing specification however it does state that the service provides training to enable short breaks provision. Please contact Nottingham City Council and Nottinghamshire County Council regarding access to regular short breaks. How to submit a Freedom of Information request to the Local Authorities can be found on their websites linked below.

Nottinghamshire County Council – <https://www.nottinghamshire.gov.uk/council-and-democracy/freedom-of-information/submit>

Nottingham City Council – <https://www.nottinghamcity.gov.uk/your-council/about-the-council/access-to-information/information-request>

If you are unhappy with the way in which your request has been handled, NHS Nottingham and Nottinghamshire Integrated Care Board (ICB) have an internal review procedure through which you can raise any concerns you might have. Further details of this procedure can be obtained by contacting Lucy Branson, Associate Director of Governance via lucy.branson@nhs.net or by writing to FOI Team at NHS Nottingham and Nottinghamshire ICB, Sir John Robinson House, Sir John Robinson Way, Arnold, Daybrook, Nottingham, NG5 6DA.

If you remain dissatisfied with the outcome of the internal review, you can apply to the Information Commissioner's Office (ICO), who will consider whether the organisation has complied with its obligations under the Act and can require the organisation to remedy any problems. Generally, the ICO cannot make a decision unless you have exhausted the complaints procedure provided by NHS Nottingham and

Nottinghamshire ICB. You can find out more about how to do this, and about the Act in general, on the Information Commissioner's Office website at: <https://ico.org.uk/for-the-public/>

Complaints to the Information Commissioner's Office should be sent to:

FOI/EIR Complaints Resolution, Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF. Telephone 0303 123 1113 or report a concern via <https://ico.org.uk/concerns/>

Yours sincerely

Freedom of Information (FOI) Officer on behalf of *NHS Nottingham and Nottinghamshire Integrated Care Board*

notts.foi@nhs.net

All information we have provided is subject to the provisions of the Re-use of Public Sector Information Regulations 2015. Accordingly, if the information has been made available for re-use under the [Open Government Licence \(OGL\)](#) a request to re-use is not required, but the license conditions must be met. You must not re-use any previously unreleased information without having the consent of NHS Nottingham and Nottinghamshire Integrated Care Board. Should you wish to re-use previously unreleased information then you must make your request in writing (email will suffice) to the FOI Lead via notts.foi@nhs.net. All requests for re-use will be responded to within 20 working days of receipt.