

Date: 22/03/2021  
Our reference: 3220

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, as of 1 April 2020 the following Clinical Commissioning Groups (CCGs), NHS Mansfield & Ashfield CCG, NHS Newark & Sherwood CCG, NHS Nottingham City CCG, NHS Nottingham North & East CCG, NHS Nottingham West CCG and NHS Rushcliffe CCG, merged to become NHS Nottingham and Nottinghamshire CCG. More information around the new NHS Nottingham and Nottinghamshire CCG can be found on our website - <https://nottsccg.nhs.uk/about-us/our-ccg/>

### Introduction

NHSE is responsible for the commissioning of “Highly specialist palliative care services for children and young adults” your request refers to the commissioning of very highly specialised palliative care services from a small number of providers nationally and is not commissioned from any Trusts in the midlands.

The Prescribed Services Manual sets out the respective commissioner responsibilities as follows:

### What NHS England commissions

**NHS England commissions** highly specialist palliative care services for children and young adults from Highly Specialist Paediatric Palliative Care Centres. These services have the following features:

- Delivered by a consultant-led multi-professional specialist palliative care team
- Providing a clinical leadership role in planning delivery and evaluation of children's palliative care services across a managed clinical network
- Led by a medical consultant working at Paediatric Palliative Care Competency Level 4
- Providing the full range of specialist paediatric palliative care interventions including use of alternative opioids
- Able to treat all children and young adults, regardless of their age

This includes services delivered on an outreach basis as part of a provider network.

### What Clinical Commissioning Groups (CCGs) commission

#### CCGs commission:

- Children's community nursing teams
- Specialist short break services/respite
- 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 CCG elements.

In the request you asked:

1. Do you have a children's palliative care service specification? **Yes**

- a. If so, please attach a copy to your response to this request.

Yes for CCGs commissioning of a children's community nursing team. The specification was reviewed immediately prior to the COVID pandemic last year and although this has not been officially contracted, is being used in practice with the exception of the element noted on page 18

- End of life support available 24 hours a day, 7 days a week, 365 days a year.

This will be fully implemented by end of April 2021. In the interim all agencies supporting a CYP at end of life determine how this 24/7 care at home is provided on an as and when basis.

Yes for CCGs commissioning of routine care delivered by a children's hospice.

See attached specification.

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? (No)

This is commissioned by NHS England however the children's community nursing team specification does acknowledge the need for personalisation including choice of place of care.

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? (No)

This is commissioned by NHS England.

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)

For the CCG commissioned elements the provision of advice and support for children and young people is either the sole purpose of the specification (support services for children and young people with palliative care needs) or the specification for community nursing and hospice care expresses the expectation that emotional and psychological support are offered directly or by referral.

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? (No)

This is commissioned by NHS England.

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)

Yes – as part of the hospice specification already shared plus a separate specification for support services for children and young people with life limiting conditions. The relevant elements from this specification are replicated below;

- Individual work
  - Individual support sessions will be provided with:
    - Children and young people with life-limiting conditions
    - Parents/carers
    - Siblings
    - Whole family



- The focus of the work can include: emotional support, dealing with loss and bereavement, parenting support, behaviour and stress management, confidence building, life skills work, health and relationships advice, practical help (benefits, housing, transport etc.) signposting to other services or agencies, advocacy, linking to community activities, opportunities for play and leisure or 'time-out' from the family, supporting families to communicate their feelings, or to plan for death.
  - Group support
    - Group support will be provided for children and young people and for parents/carers and siblings. Groups will be planned to meet identified needs, where a group setting seems to be a more effective way of achieving outcomes and there is an identified group of service users with common needs.
    - The focus of groups may include parenting support, stress management, communicating with children, having a sibling with a life-limiting condition, loss and bereavement.
    - Groups for children will use play and activity-based methods and will provide an opportunity to develop peer support and have fun together. Links may be developed with other agencies, to enable groups to be run in local communities.
  - Programme of activities
    - A schedule of outings, events and activities will be provided for families and children. This will create opportunities for families to have fun together, increase confidence in accessing leisure facilities and provide short breaks, where needed.
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)

Yes for children's community nursing.

Yes for advice under the hospice care specification – which includes offering medical advice to community teams and GPs from the hospice medical team

No for 24 hour access to a consultant -There is not currently a specification for access to 24 hour advice from a paediatric consultant but funding has been increased for this specific function in both creating a regional approach to maximise expertise and cover; and to bolster local consultant time. This service is due to commence quarter 1 2021 (April – June 2021)

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)

Yes for the children's community nursing element in their role in meeting health needs for the children who are eligible for short breaks. The CCG and LA work together in planning this provision which will include children and young people with a life limiting condition, but the LA are responsible for ensuring there is suitable provision and the eligibility to access short breaks.

The CCG also directly commission 10 nights of specialist residential palliative respite care per child over a year as in the attached hospice specification. The hospice criterion is families with a child who has a life-limiting condition and is not expected to live into adulthood.

If you are unhappy with the way in which your request has been handled, NHS Nottingham and Nottinghamshire Clinical Commissioning Group 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](mailto:lucy.branson@nhs.net) or by writing to NHS Nottingham and Nottinghamshire CCG, 1 Standard Court, Park Row, Nottingham, NG1 6GN.



If you remain dissatisfied with the outcome of the internal review, you can apply to the Information Commissioner's Office, 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 Clinical Commissioning Group formerly known as NHS Mansfield and Ashfield Clinical Commissioning Group, NHS Newark and Sherwood Clinical Commissioning Group, NHS Rushcliffe Clinical Commissioning Group, NHS Nottingham West Clinical Commissioning Group, NHS Nottingham City Clinical Commissioning Group and Nottingham North and East Clinical Commissioning Group. 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: <https://ico.org.uk/concerns/>

Yours sincerely

Freedom of Information Officer on behalf of *NHS Nottingham and Nottinghamshire Clinical Commissioning Group formerly known as NHS Rushcliffe Clinical Commissioning Group, NHS Nottingham West Clinical Commissioning Group, NHS Nottingham City Clinical Commissioning Group, NHS Nottingham North and East Clinical Commissioning Group, NHS Mansfield and Ashfield Clinical Commissioning Group and NHS Newark and Sherwood Clinical Commissioning Group.*

[notts.foi@nhs.net](mailto: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 Clinical Commissioning Group. 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](mailto:notts.foi@nhs.net). All requests for re-use will be responded to within 20 working days of receipt.*

