

Our Ref: FOI 009969

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11 March 2021

Reply sent by email to: Dan.Steer@togetherforshortlives.org.uk

Dear Dan

Re: Request for information under the Freedom of Information Act 2000

Thank you for your email dated 15 February 2021, making a request under the Freedom of Information Act 2000 for access to information which may be held by NHS Greater Preston Clinical Commissioning Group (CCG).

Please find detailed below NHS Greater Preston CCG's response to your request, which is formatted as follows:-

1. Details of NHS Greater Preston CCG's decision in regard to the information requested.
2. A schedule of all the records covered by your request.
3. A statement concerning copyright and re-use of public sector information.
4. Details of how you can appeal this decision should you wish to do so.

This letter addresses each of these parts in turn:-

1. Decision

I can confirm that NHS Greater Preston CCG holds the information requested.

2. Schedule of records/FOI response

Request:

Do you have a children's palliative care service specification? (Yes/No). If so, please attach a copy to your response to this request.

Response:

No. However, NHS Greater Preston CCG and NHS Chorley and South Ribble CCG (Central Lancashire CCGs) are currently developing a service specification for a 'specialist' children and young people palliative care and End of Life service. The service specification is currently being developed in partnership with the local acute provider Lancashire Teaching Hospitals NHS Foundation Trust (LTHTR)) and the local children's hospice – Derian House Children's Hospice.

This specialist service provision will build upon, and complement, the core/universal service offers provided from Derian House as part of the wider model of the Hospice which is funded via different charitable sources and grant funding arrangements. The service specification will only relate to the provision of the specialist service as part of the Central Lancashire offer, this will also coincide with a wider Children and Young People's (CYP) Palliative and End of Life Care strategy that is being developed and implemented across the Healthier Lancashire and South Cumbria Integrated Care System (ICS), that incorporates the recruitment of a dedicated Consultant Lead post for the system.

The intention is that this post will be hosted within the specialist service commissioned via the Central Lancashire CCGs.

Request:

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)

Response:

As mentioned above, the service specification is currently in development. It will include reference to all the best practice guidance and the most recent policy and recommendations from national and regional documents. It is the intention that CYP and their families will be at the centre of all the design and developments of the services and will be involved throughout all of the care planning processes.

Request:

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)

Response:

The specialist service specification will not explicitly cover all elements of the palliative care pathways and services, however, it is expected that there will be a named lead where appropriate and be developed within the integrated partnership between the acute and the hospice service provision.

Request:

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)

Response:

This will be detailed within the specification, however, it is also an expectation as part of the wider palliative care services and core/universal offers.

Request:

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)

Response:

This will be detailed within the specification, however, it is also an expectation as part of the wider palliative care services and core/universal offers.

Request:

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)

Response:

This will be detailed within the specification, however, it is also an expectation as part of the wider palliative care services and core/universal offers.

Request:

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)

Response:

This will be detailed within the specification, however, it is also an expectation as part of the wider palliative care services and core/universal offers.

Request:

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)

Response:

This will be detailed within the specification, however, it is also an expectation as part of the wider palliative care services and core/universal offers.

3. Copy and reuse of public sector information provided in FOI response

Most of the information provided by NHS Greater Preston CCG in response to Freedom of Information Act 2000 requests will be subject to copyright protection. In the majority of cases the information will be owned by NHS Greater Preston CCG. The copyright for other information may be owned by another person or organisation, as indicated in the

information itself: in this case you must apply to the copyright owner to obtain their permission.

You are free to use any information supplied for your own use, including for non-commercial research purposes. It may also be used for the purposes of news reporting. However, any other type of re-use, for example, by publishing the information or issuing copies to the public will require the permission of the copyright owner.

4. Right of appeal to FOI response

If you are dissatisfied 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 are entitled to complain in the following way:

Initially you should complain in writing to the freedom of information officer, either by email on gpccg.foi@nhs.net or post to Chorley House, Lancashire Business Park, Leyland, PR26 6TT, specifying why you feel you have been wrongly denied access to the information requested. The freedom of information officer will ensure your complaint is investigated under NHS Greater Preston CCG's internal processes and provide you with a written response within 20 working days.

If you are not content with the outcome of your complaint, you may apply directly to the Information Commissioner's Office (ICO) for a decision. Generally, the ICO cannot make a decision unless you have exhausted the complaints procedure provided by NHS Greater Preston CCG.

Yours sincerely



Helen Curtis
FOI Lead
Head of Quality and Performance