

Our ref:
Please contact:
Email:
Personal assistant:
Direct tel:

13 May 2024

Re: Your request for information under the Freedom of Information Act 2000
Ref no: FOI-3993-LSC

Thank you for your request dated 12 April 2024.

We can confirm that the ICB does hold the information you requested.

Please find our response to your questions below:

1. Please set out how much money your integrated care board spent on hospice care for children and young people with life-limiting or life-threatening conditions between 6 April 2023 and 5 April 2024. Please provide a total, in addition to a breakdown of funding per children's hospice organisation.

Please refer to the attached document.

Please note that funding went directly through NHS England in 2023/24, so these figures have not been provided in case they are incorrect or cause confusion.

2. Please set out the arrangement through which this money was paid in 2023/24 – was this by standard contract

As per question 1.

3. Please set out how many children and young people with life-limiting or life-threatening conditions who live in your integrated care board footprint accessed hospice care between 6 April 2023 and 5 April 2024. Please provide a total, in addition to a breakdown of funding per hospice organisation.

In 2023/24 we had a contract and 2 Grant agreements in place with Derian House.

For the Contracted element, Derian House provided:

Activity	Number of interventions (this can consist of a counselling session)
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	being delivered at home, a respite visit etc.
Bereavement Support	23
Counselling	14
Derian at Home (EOL Care)	34
Derian at Home (Respite)	73
Family Support Services	14
Hospice respite nights	37
Perinatal	95
Wellbeing Service	103
Youth Work	130
Deceased	7

Activity	Number of CYP interventions (this can consist of a counselling session delivered at home, a respite visit etc.).
Bereavement Support	86
Counselling	92
Derian at Home (EOL Care)	75
Derian at Home (Respite)	60
Family Support Services	23
Hospice respite nights	58
Perinatal	89
Sibling Care	118
Wellbeing Service	168
Counselling	92

Activity	No. of CYP Interventions	No. of Family Interventions
Bereavement Support	25	59
Counselling	43	42
Derian at Home (EOL Care)	0	0
Derian at Home (Respite)	41	40
Family Support Services	23	0
Hospice respite nights	80	0
Perinatal	85	0
Sibling Care	71	83
Wellbeing Service	138	17
Youth Work / Young adults service	161	0
Deceased	2	

Derian House

NHS Standard Contract	£260,000
Grant – Central Lancashire	£44,430.90
Grant – Pennine	£90,460.12

Note: The ICB have no contracts in place with Brian House or Jigsaw and therefore do not have

any data from these Providers.

4. Please set out how many children and young people with life-limiting or life-threatening conditions who live in your integrated care board footprint could benefit from children's hospice care.

A North West point prevalence study was undertaken by Lancaster University in February 2023. This study identified 344 children and young people with palliative care needs in Lancashire and South Cumbria. The study provided insight into the demographics of these children and young people

- **8% were babies under one, 93% children over one**
- **Highest category were children 6-10 years (27%), followed by 1-5 years (26%) and 11-15 years (23%)**
- **55% of children and young people were male**
- **67% were from a white ethnic background, 16% were from a South Asian background. This highlights an over representation of the South Asian Community where general ethnicity data highlights 8% of the North West population is South Asian. Therefore there is more than expected based on population demographics. Conversely less children from the South Asian community were actively in treatment during in the point prevalence study (one week in February)**
- **The main condition for palliative and end of life care needs was neurological (37%), followed by respiratory (13%), congenital (13%), circulatory (10%), oncology (8%), metabolic (5%), gastrointestinal (4%), genitourinary (2%), Haematology (1%)**
- **The services supporting children in order of highest access was community teams (37%), hospice (21%), general hospitals (20%) and children's specialist hospitals (19%)**
- **The prognosis of those children were highlighted as**
 - **2% in the last days/weeks of life**
 - **7% increasing instability or progressive deterioration (Months)**
 - **22% increasing instability or progressive deterioration (Years)**
 - **28% death before adulthood is not unexpected**
 - **33% diagnosis of a potential life-limiting condition, survival into adulthood expected**

The information from the prevalence study provides the system with additional intelligence to help inform and plan services to meet need.

Please note that not all of these children will require or choose hospice care.

5. Please set out how much money your integrated care board plans to spend on hospice care for children and young people with life-limiting or life-threatening conditions between 6 April 2024 and 5 April 2025, excluding any money that is set to be paid as part of the NHS England Children's Hospice Grant. Please provide a total, in addition to a breakdown of funding per hospice organisation.

As per question 1.

6. Please set out the arrangement through which this money will be paid in 2024/25 – by standard contract, service level agreement, grant arrangement, spot purchases or by other means.

The ICB will be issuing NHS Standard Contracts for the 2024/25 funding.

Right of Appeal

Should you require any further information or clarification regarding this response please do not hesitate to contact us. If you are dissatisfied with the response, you are entitled to request an internal review which should be formally requested in writing and must be within two calendar months from the date this response was issued.

To request an internal review

You can request this by contacting the FOI team by email at MLCSU.FOITeam@nhs.net or by post to Jubilee House, Lancashire Business Park, Leyland, PR26 6TR, specifying why you require a review.

If you are not content with the outcome of your internal review, 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 CCGs FOI complaints procedure. The ICO can be contacted at:

Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF
www.ico.gov.uk

Yours sincerely

Sam Proffitt – Chief Finance Officer

**On behalf of Kevin Lavery
ICB Chief Executive**