

Reference: FOI.ICB-2627/028

Subject: Children's Hospice Services and Spend

I can confirm that the ICB does hold some of the information requested; please see responses below:

QUESTION	RESPONSE
	<p>The questions below which I would like you to answer are designed to help me understand:</p> <ul style="list-style-type: none"> • how much money NHS Bristol, North Somerset and South Gloucestershire ICB spent on hospice services for babies, children and young people with life-threatening conditions, life-shortening conditions or with severe medical complexity. in 2025/26, excluding the £26 million of funding that NHS England asked every ICB to distribute. • how many babies, children and young people with life-threatening conditions, life-shortening conditions or with severe medical complexity in the NHS Bristol, North Somerset and South Gloucestershire ICB footprint accessed hospice care during 2025/26 • how much money NHS Bristol, North Somerset and South Gloucestershire ICB plans to spend on hospice services for babies, children and young people with life-threatening conditions, life-shortening conditions or with severe medical complexity during 2026/27, excluding any funding it will distribute from the first-year allocation of the £80 million three-year funding commitment for children's hospices that NHS England has asked ICBs to pass on. <p>Where your integrated care board came into existence on or after 1 April 2026 through the merger or reconfiguration of one or more predecessor integrated care boards (ICBs), please treat this request as applying to all relevant predecessor ICBs whose functions, responsibilities or records are now held by your organisation.</p> <p>In these circumstances, responses should include all relevant spending, activity, and data relating to those predecessor ICBs for the periods covered by this request. Please provide an aggregated total for the current ICB footprint, alongside a clearly labelled breakdown by each predecessor ICB.</p>

In order to help you meet my request, I provide definitions to the terms I use in my questions below:

Life-threatening conditions

Conditions for which disease-modifying or life-prolonging treatment may be available but may fail, or where intensive therapies and interventions are required to sustain or prolong life. These conditions carry a significant risk of premature death even if treatment is pursued.

Life-shortening conditions

Conditions where death in childhood or early adulthood is likely due to the progressive nature of the condition or the absence of effective disease-modifying treatment.

Severe medical complexity

Children and young people with severe medical complexity and vulnerability, including multi-system involvement, profound neurological impairment, technology dependence, or extreme frailty, where there is a significant risk of life-threatening events.

Children and young people

Babies, children and young people aged 0-25.

1. Please set out how much money your integrated care board and/or any predecessor integrated care boards it now represents spent on hospice care for babies, children and young people with life-threatening conditions, life-shortening conditions or with severe medical complexity between 6 April 2025 and 5 April 2026. Please provide a total, in addition to a breakdown of funding per children’s hospice organisation.

This is the spend for the financial year 2025/26 (1 April 2025-31 March 2026), which closely aligns to the dates requested:

Children’s Hospice South West (CHSW) - £715,000
Jessie May Hospice - £298,000

	<p>Please note: the ICB only commissions children's hospice services for CYP between 0-19 years old, patients over the age of 19 would receive end of life care from our commissioned adult end of life providers.</p>																												
<p>2. Please set out the arrangement through which this money was paid in 2025/26 – was this by block contract, standard contract, service level agreement, grant arrangement, spot purchases or other by means.</p>	<p>The Jessie May Trust and CHSW both hold standard NHS contracts (Short form) and have fixed activity based finance agreements. For patients aged 0-19.</p>																												
<p>3. Please set out how many babies, children and young people with life-threatening conditions, life-shortening conditions or with severe medical complexity who live in your integrated care board footprint and/or the footprint of any predecessor integrated care boards it now represents accessed hospice care between 6 April 2025 and 5 April 2026.</p>	<p>Last available data for patients aged 0-19:</p> <p>CHSW:</p> <p>Reports activity volumes rather than a unique count of children. This means the same child may be recorded in more than one category (for example, receiving home visits as well as bed nights in the hospice).</p> <table border="1" data-bbox="1081 954 2047 1426"> <thead> <tr> <th></th> <th>Bed nights</th> <th>Day Visits</th> <th>Bereavement visits</th> <th>Home visits</th> <th>Hospital visits</th> <th>Zoom sessions</th> </tr> </thead> <tbody> <tr> <td>Q1 (Apr-Jun)</td> <td>167</td> <td>37</td> <td>21</td> <td>4</td> <td>13</td> <td>0</td> </tr> <tr> <td>Q2 (Jul-Sept)</td> <td>139</td> <td>56</td> <td>14</td> <td>11</td> <td>5</td> <td>16</td> </tr> <tr> <td>Q3 (Oct-Dec)</td> <td>164</td> <td>86</td> <td>26</td> <td>19</td> <td>11</td> <td>47</td> </tr> </tbody> </table>		Bed nights	Day Visits	Bereavement visits	Home visits	Hospital visits	Zoom sessions	Q1 (Apr-Jun)	167	37	21	4	13	0	Q2 (Jul-Sept)	139	56	14	11	5	16	Q3 (Oct-Dec)	164	86	26	19	11	47
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	<p>Jessie May: Total number of children supported (by quarter): Q1 (Apr-Jun) - 96 children Q2 (Jul-Sept) - 99 children Q3 (Oct-Dec) - 102 children</p>												
<p>4. Please set out how many babies, children and young people with life-threatening conditions, life-shortening conditions or with severe medical complexity who live in your integrated care board footprint could benefit from children’s hospice care.</p>	<p>The ICB does not hold this information. We advise you to contact the hospice organisations directly.</p> <p>The Jessie May Trust: Contact - Jessie May CHSW: Contact us Childrens Hospice South West</p>												
<p>5. Please set out how much money your integrated care board plans to spend on hospice care for babies, children and young people with life-threatening conditions, life-shortening conditions or with severe medical complexity between 6 April 2026 and 5 April 2027, excluding any funding it will distribute from the first-year allocation of the £80 million three-year funding commitment for children’s hospices that NHS England has asked ICBs to pass on.</p>	<table border="1" data-bbox="1084 778 2056 954"> <thead> <tr> <th>Provider</th> <th>ICB Contribution</th> <th>NHSE Grant Value</th> <th>Total</th> </tr> </thead> <tbody> <tr> <td>Jessie May</td> <td>£180,536.48</td> <td>£125,000</td> <td>£305,536.48</td> </tr> <tr> <td>CHSW</td> <td>£393,690.79</td> <td>£336,000</td> <td>£729,690.79</td> </tr> </tbody> </table>	Provider	ICB Contribution	NHSE Grant Value	Total	Jessie May	£180,536.48	£125,000	£305,536.48	CHSW	£393,690.79	£336,000	£729,690.79
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<p>6. Please set out the arrangement through which this money will be paid in 2026/27 – by block contract, standard contract, service level agreement, grant arrangement, spot purchases or other by means.</p>	<p>The Jessie May Trust and CHSW both hold standard NHS contracts (Short form) and have fixed activity based finance agreements. For patients aged 0-19.</p>												

The information provided in this response is accurate as of 18 May 2026 and has been approved for release by Helena Fuller, Deputy Director of Business, Strategy and Planning for NHS Bristol, North Somerset and South Gloucestershire ICB.