

Reference: FOI 43491 SX ICB

Subject: Children and Young People with Life-limiting or Life-threatening Conditions

I can confirm that we have now completed the search for the information requested, please see responses below:

Please note: As of 1 July 2022, NHS Brighton and Hove CCG, NHS East Sussex CCG and NHS West Sussex CCG have closed, and the functions of the CCGs have transferred to the new NHS organisation - NHS Sussex Integrated Care Board.

QUESTION	RESPONSE
<p>In order to help you meet my request, I provide definitions to the terms I use in my questions below:</p> <p><i>Life-limiting and life-threatening conditions</i></p> <p>“Life-limiting conditions are those for which there is no reasonable hope of cure and from which children will die. Some of these conditions cause slow deterioration over time rendering the child increasingly dependent on parents and carers.</p> <p>Life-threatening conditions are those for which curative treatment may be feasible but can fail, such as cancer.”</p> <p><i>Children and young people</i></p> <p>Babies, children and young people aged 0-25.</p>	
<p>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 2022 and 5 April 2023. Please provide a total, in addition to a breakdown of funding per children’s hospice organisation.</p>	<p>For 0 – 18 years: Funding is currently allocated via NHSEI central grants to CYP Hospices (0-18 years), the ICB does not currently have access to these details or breakdown per Hospice.</p> <p>For 18 – 25 years: ICB grant contributions to adult hospices cover patients aged 18 years and over. The allocation is not split by age ranges therefore we are unable to provide figures for the 2022/23 spend for the 18-25 year old cohort.</p>

<p>2. 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 2022 and 5 April 2023. Please provide a total, in addition to a breakdown of funding per hospice organisation.</p>	<p>For 0 – 18 years: The ICB does not currently hold this information. This would need to be a direct request to Hospice Providers.</p> <p>For 18 – 25 years: The ICB does not hold this patient information.</p> <p>ICB grant contributions to adult hospices cover patients aged 18 years and over. The allocation is not split by age ranges therefore we are unable to provide figures for the 2022/23 spend for the 18-25 year old cohort.</p>
<p>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 could benefit from children’s hospice care.</p>	<p>For 0 -18 years: The ICB does not currently have this information in one place given the nature of services and the range of life limiting conditions.</p> <p>Sussex ICB is currently working with key stakeholders including Chestnut Tree and Demelza Children’s Hospices to map and benchmark provision and numbers and we will be in a clearer position once this has been completed.</p> <p>For 18 – 25 years: The ICB does not hold this information.</p>
<p>4. 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 2023 and 5 April 2024 ?. Please provide a total, in addition to a breakdown of funding per hospice organisation.</p>	<p>For 0 -18 years: As already mentioned above Hospice grants are set by NHSEI and the ICB does not currently provide additional funding streams. On a case by case basis, some CYP eligible for continuing care packages may require additional funds for their hospice care if there is a need beyond the usual 2 weeks Hospice offer.</p> <p>For 18 – 25 years: ICB grant contributions to adult hospices cover patients aged 18 years and over. The allocation is not split by age ranges therefore we will be unable to provide figures for the 2023/24 spend for the 18-25 year old cohort.</p>

The information provided in this response is accurate as of 5 May 2023 and has been authorised for release by NHS Sussex ICB.