Dear

Further to your request for information dated 1 June 2017 the information requested is below

1. **Do you commission palliative care for children and young people with life-limiting and life-threatening conditions between the ages of 0 and 25? (yes/no)** If yes, how much did you spend on children’s palliative care in 2016/17?

   NHS Dartford Gravesham and Swanley Clinical Commissioning Group (CCG) commissions palliative care for children via our local Hospice as part of a wider contract for children’s and adult’s palliative and end of life care. As such, there is no definitive amount set to support the children’s service, but the total spend for both adults and children’s is about £1.25m per year. Our community provider, Kent Community Health Foundation Trust, provide a Community Children’s Nursing service.

   NHS Dartford Gravesham and Swanley CCG will also commission bespoke care packages for children and young people who meet Continuing Care / Continuing Healthcare criteria where some of these patients will meet have “life limiting / life-threatening conditions”. The CCG’s database does not, however, record specifically whether a patient supported by our team has “life limiting / life-threatening conditions” and it is unfortunately not possible for the CCG to automatically identify spend associated with this patient cohort.

2. **Do you have a published strategy or care pathway for children with life-limiting and life-threatening conditions? If so, please provide a link or an attachment.**
The CCG does not have a specific strategy but are working on producing one during 2017/18 for both adults and children’s Palliative and End of Life care. The CCG’s local provider, Ellenor Hospice, may have their own children’s strategy and as such should be contacted directly. If you have not already done so you may wish to contact Ellenor Hospice at

Ellenor
Coldharbour Road
Gravesend
Kent DA11 7HQ

Email info@ellenor.org

The CCG’s Specialist Assessment and Placements Team (SAPT) are stakeholders within the Kent & Medway Children and Young People’s Palliative Care Forum which is made up of professional representatives from across Kent and Medway spanning health, education and social care where members seek to improve the care delivered to patients. This includes care pathways as attached.

3. Did you ask for your local sustainability and transformation plan to include palliative care for children with life-limiting and life-threatening conditions? (Yes/No).

Not directly, however the CCG’s lead provider for children’s palliative and End of Life care is part of the working group for the CCG’s local STP.

4. Do you assess numbers and needs of children and young people with life-limiting and life-threatening conditions between the ages of 0 and 25 among the population you serve (yes/no)? If yes, please tell us how. Please also tell us how many children and young people with life-limiting and life-threatening conditions there are in your area.

High level analysis is undertaken by the CCG regularly to better understand the population we serve. Direct analysis of children with life-limiting and life-threatening conditions is undertaken by our community providers who work directly with them. They liaise closely with the acute trusts and questions relating to the analysis they undertaken on behalf of children should be directed to them.

The Kent & Medway Children and Young People Palliative Care Forum is aware of activity across Kent & Medway as stakeholder professionals actively share and review this information.

On an individual patient basis the Specialist Assessments and Placement Team (SAPT) will perform a needs assessment as required to establish care and support packages.
5. Do you jointly commission palliative care for children and young people with life-limiting and life-threatening conditions between the ages of 0 and 25 with your local authorities in a way which is consistent with the Children and Families Act 2014? (yes/no)

NHS Dartford Gravesham and Swanley Clinical Commissioning Group works in partnership with Kent County Council through the integrated children’s commissioning team although the CCG does not specifically jointly commission palliative care.

6. Do you commission palliative care which enables a child or young person to receive end of life care at home if they wish to do so? (yes/no)

Yes, this is provided via Ellenor Hospicial

Palliative care children and young people who met eligibility criteria for Continuing Care / Continuing Healthcare would have end of life care funded at home where clinically appropriate.

7. Do you commission a rapid transfer process for children and young people with life-limiting conditions to allow urgent transfer to the preferred place (for example from the intensive care unit to their home or to a children’s hospice)? (yes/no)

Yes, this is provided and co-ordinated by Ellenor Hospice and a number of other providers such as the acute trusts.

8. Do you take steps to integrate assessments, plans and services for children and young people with life-limiting and life-threatening conditions between the ages of 0 and 25, including those without a special educational need and disability (yes/no)? If yes, please tell us how (For example, using education, health and care plans).

Where children and young people receive support from across health, social care and education then the CCG will integrate assessments.

9. Do you offer personal budgets to children and young people with life-limiting and life-threatening conditions? If yes, how many children and young people with life-limiting and life-threatening conditions in your area have a personal budget?

Within NHS Dartford Gravesham and Swanley Clinical Commissioning Group’s area there are two children and young people who have personal health budgets.

10. Do you take steps to make sure that young people with life-limiting and life-threatening conditions can access palliative care services which are
appropriate to their age and developmental stage (yes/no)? If yes, please tell us how.

Age appropriate care and support is offered to all patients and their families as children’s nurses will always direct care as appropriate to the age and needs of patients.

11. Do you take steps to make sure that young people with life-limiting and life-threatening conditions experience smooth transitions from children’s to adults’ palliative care services (yes/no)? If yes, please tell us how.

This is managed by Ellenor Hospice who has a robust transition process for those children moving into adult care.

12. Do you commission any of the following services for children with life-limiting or life-threatening conditions? If yes, please state which outcomes you ask service providers to achieve and how much you spent on them in 2016/17:

- A level 4 paediatric palliative care consultant (yes/no)?

  Not specifically.

- Consistent with the NICE clinical guideline ‘End of Life Care for Infants, Children and Young people’, a multidisciplinary team that includes the following as a minimum (yes/no)?
  
  - a paediatric palliative care consultant
  - a nurse with expertise in paediatric palliative care
  - a pharmacist with expertise in specialist paediatric palliative care
  - experts in child and family support who have experience in end of life care (for example in providing social, practical, emotional, psychological and spiritual support)

Ellenor Hospice has a dedicated children’s nursing team who deliver support to palliative and End of Life Care children in the community. They do this with the support and guidance of consultants in the acute trusts who have overall responsibility for the child, the duty doctors and palliative care consultants at the hospice, the pharmacist support within the Hospice and via the support provided from the community nurses at Kent Community Health Foundation Trust. There is no dedicated spend on children’s services within Ellenor Hospice as they get a single supporting payment each year for both adults and children. The hospice has over 60 Key Performance Indicators (KPIs) to report each quarter, several of which reflect delivery of the children’s service. These are reviewed and monitored regularly by NHS Dartford Gravesham and Swanley Clinical Commissioning Group.

- Acute children’s palliative care nurses which provide children’s palliative care (yes/no)?
Yes, we have a team of palliative care nurses within our local trust who will provide support and guidance to all patients with a palliative condition. They also have support and guidance from specialist nurses at Ellenor Hospice.

- **Community children’s nurses which provide children’s palliative care (yes/no)?**
  
  Yes, our children’s community nurses provide palliative care with support and guidance from specialist nurses at Ellenor Hospice.

- **Voluntary sector children’s palliative care services (including children’s hospice services) (yes/no)? If yes, which voluntary sector services do you commission and how much did you spend on them in 2016/17?**
  
  Yes, we have a dedicated children’s team with Ellenor Hospice. Prices for their contract already mentioned in our replies above.

- **Community paediatricians which provide children’s palliative care (yes/no)?**
  
  No, we do not have a community paediatrician specifically for palliative care.

- **Emotional and psychological support for children and their families (yes/no)?**
  
  Support time is limited but is provided via Ellenor Hospice.

- **Bereavement care - to families before a child under the age of 1 has died (yes/no)?**
  
  Yes provided via Ellenor Hospice although support time is limited.

- **Bereavement care - to families after a child under the age of 1 has died (yes/no)?**
  
  Yes provided via Ellenor Hospice although support time is limited.

- **Bereavement care - to families before a child or young person aged 1 – 25 has died (yes/no)?**
  
  Yes provided via Ellenor Hospice although support time is limited. Families within NHS Dartford Gravesham and Swanley Clinical Commissioning Group's area may also access support from Demelza House.

- **Bereavement care - to families after a child or young person aged 1 – 25 has died (yes/no)?**
Yes provided via Ellenor Hospice although support time is limited. Families within NHS Dartford Gravesham and Swanley Clinical Commissioning Group’s area may also access support from Demelza House.

- **Equipment - including services which provide wheelchairs and services to maintain and repair equipment (yes/no)?**

  Yes – ordering of equipment is co-ordinated by a number of community and acute providers.

13. Do you commission any of the following services to provide care out of hours and at weekends for children with life-limiting or life-threatening conditions? We define ‘out of hours and at weekends’ as 6:30pm – 8am on weekdays and all day on Saturdays, Sundays and Bank Holidays.

- **A level 4 paediatric palliative care consultant (yes/no)?**

  No

- **Consistent with the NICE clinical guideline ‘End of Life Care for Infants, Children and Young people’, a multidisciplinary team that includes as a minimum:**

  - a paediatric palliative care consultant
  - a nurse with expertise in paediatric palliative care
  - a pharmacist with expertise in specialist paediatric palliative care
  - experts in child and family support who have experience in end of life care (for example in providing social, practical, emotional, psychological and spiritual support)

  Ellenor Hospice provide 24/7 support for children and their families via a dedicated telephone number into a team of nurses and home visits where required.

- **Acute children’s palliative care nurses which provide children’s palliative care (yes/no)?**

  We have a team of palliative care nurses within our local trust who provide support and guidance to tall patients with a palliative condition 7 days a week although mainly within business hours. Out of hours telephone advice is available.

- **Community children’s nurses which provide children’s palliative care (yes/no)?**

  Our children’s community nurses can provide palliative care support and guidance 24/7 via telephone and visits where required. They link closely with the Ellenor Children’s nurses.
• Voluntary sector children’s palliative care services (including children’s hospice services) (yes/no)? If yes, which voluntary sector services do you commission and how much did you spend on them in 2016/17?

Yes, we have a dedicated children’s team with Ellenor Hospice who provide 24/7 support for children and their families via a dedicated telephone number into a team of nurses and home visits where required. Prices for their contract already mentioned above

• Community paediatricians which provide children’s palliative care (yes/no)?

No we do not have a community paediatrician specifically for children’s palliative care as per our previous comment.

• Emotional and psychological support for children and their families (yes/no)?

Yes, provided by Ellenor Hospice. Families within NHS Dartford Gravesham and Swanley Clinical Commissioning Group’s area may also access support from Demelza House.

• Bereavement care - to families before a child under the age of 1 has died (yes/no)?

Yes, provided by Ellenor Hospice. Families within NHS Dartford Gravesham and Swanley Clinical Commissioning Group’s area may also access support from Demelza House.

• Bereavement care - to families after a child under the age of 1 has died (yes/no)?

Yes, provided by Ellenor Hospice. Families within NHS Dartford Gravesham and Swanley Clinical Commissioning Group’s area may also access support from Demelza House.

• Bereavement care - to families before a child or young person aged 1 – 25 has died (yes/no)?

Yes, provided by Ellenor Hospice. Families within NHS Dartford Gravesham and Swanley Clinical Commissioning Group’s area may also access support from Demelza House.

• Bereavement care - to families after a child or young person aged 1 – 25 has died (yes/no)?

Yes, provided by Ellenor Hospice. Families within NHS Dartford Gravesham and Swanley Clinical Commissioning Group’s area may also access support from Demelza House.
• Equipment - including services which provide wheelchairs and services to maintain and repair equipment (yes/no)?

Yes ordering of equipment is co-ordinated by a number of community and acute providers and emergency cover out of hours.

14. Do you commission the following services to children and young people with life-limiting and life-threatening conditions between the ages of 0 and 25 (yes/no)? If yes, please state how much you spent on them in 2016/17:

• short breaks (respite)
• step-down care
• end of life care.

The CCG does commission some of these services and some of these are in partnership with Kent County Council.

15. Are you implementing the NICE clinical guideline ‘End of Life Care for Infants, Children and Young People: Planning and Management’ (yes/no)? If yes, please tell us about the steps you are taking.

All providers are contracted to deliver services to the highest standards possible in line with NICE guidance and the CCG is working with providers to ensure the requirements of the Clinical Guideline are reviewed and implement, where appropriate.


This is something that the CCG’s local End of Life Care locality group will be reviewing in due course as all local providers are represented and we can gain a system wide view of progress against national standards.

If you have any queries or concerns please contact me. Please remember to quote the reference number above in any future communications.

If you are unhappy with the service that you have received in relation to your request and wish to make a complaint or request a review of our decision you should write to Complaints. NHS Dartford Gravesham and Swanley Clinical Commissioning Group 2nd Floor Gravesham Civic Centre Gravesend Kent DA12 1AU or email at dqscq.complaints@nhs.net

If you are not content with the outcome of your complaint or review, you may apply to the Information Commissioner for a decision. Generally the ICO cannot make a
decision unless you have exhausted the complaints procedure provided by the Clinical Commissioning Group. The Information Commissioner can be contacted at:

Information Commissioners Office,  
Wycliffe House,  
Water Lane,  
Wilmslow,  
Cheshire  
SK9 5AF  
Telephone: 08456 306060 or 01625 54 57 45  
www.ico.gov.uk

Please remember to quote the reference number above in any future communications.