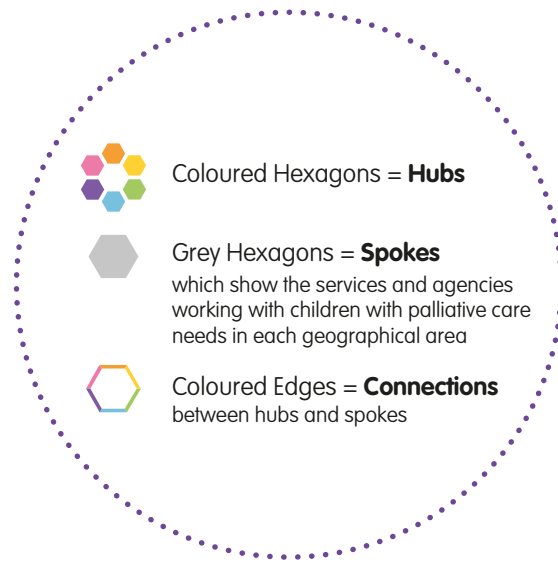


## Hub & Spoke Model (Managed Clinical Network)

The 24/7 care model proposing six hubs across the region working within specified geographical areas:



### Hubs and spokes work together:

- Sharing information
- Education
- Clinical guidelines



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## Closing the Gap in Children's Palliative and End of Life Care:

A Strategy for Yorkshire and Humber 2018 - 2023



**Vision:**  
To close the gap and ensure that every child with a life-limiting condition has access to high quality 24/7 children's palliative care wherever, however and whenever it is needed.

### Strategic Aims

To raise standards and share best practice in the provision of children's palliative care services

Identify gaps and challenges in children's palliative care service provision and respond to them

To integrate services and join things up for babies, children, young people and their families

### Strategic Objectives

Achieve all outcomes set out within NICE guidelines across region.

All staff working with babies, children and young people with life-limiting conditions have access to high quality training and work-force development

All babies, children and young people at end of life and being cared for at home have 24-hour access to both children's community nursing and advice from a consultant

Develop a regional database of children with life limiting conditions

Set up a fully funded Managed Clinical Network in children's palliative care

### Key Performance Indicators

Percentage of organisations in the region complying with NICE guidelines (measured via benchmarking tool and monitoring data)

Percentage of staff attending training sessions annually:  
Palliative Care conference delivered annually

Percentage of teams who can provide 24/7 children's community nursing access when required. The establishment of a palliative medical advice line (daytime hours initially)

Regional database developed and in use

Fully funded Managed Clinical Network developed and percentage of trusts attending



## Our Vision

To close the gap and ensure that every child with a life limiting condition has access to high quality 24/7 paediatric palliative care wherever, however and whenever it is needed.

## Our Mission Statement

The aim of the Yorkshire and Humber Children's Palliative Care Network is to develop an appropriate and adaptable model of care for all children and young people with life limiting and life threatening conditions across the Yorkshire and Humber region, according to need. The focus is to provide choice to families and reduce variation in palliative and end of life care by working together to raise standards for all.



## Closing the Gap in Children's Palliative and End of Life Care:

### A Strategy for Yorkshire and Humber 2018 - 2023

In the region there are estimated to be in excess of 3740 children living with life-limiting or life-threatening conditions and of these approximately 270 children die each year. Children with life-limiting conditions (LLC) often require numerous hospital admissions and, in the locations where community nurses are not available 24 hours a day 7 days a week, there is an increased risk of additional, unnecessary hospital admissions, especially towards end of life. This may not be what children and their families want and it has a financial cost to the NHS which could be avoided. The cost of a hospital admission for a paediatric critical care bed ranges from £849 per day to £4824 per day (NICE 2016). Additionally there is social, emotional and financial cost to families, including loss of working days and income as well as the psychological distress to the child and family. However, it is recognised that there are times when a hospital stay is unavoidable and necessary.

Currently high quality respite and palliative care is available to babies, children and young people with life limiting conditions who have been referred to one of the 4 children's hospices in the region: Bluebell Wood, St Andrews, Martin House and Forget Me Not Hospices. The ambition outlined in this strategy is to improve services for those children who do not have care provided by the hospices, or whose families chose to have care at home where both hospice and community care can work side by side. To support these ambitions it is necessary to have a managed clinical network with a network coordinator to support the clinical and educational activities. The current network coordinator has been funded for 2 years by contributions from the 4 hospices and from Leeds CCG but ongoing funding of a managed clinical network and the network coordinator is needed to continue to grow the network.

There are geographical gaps in the provision of funded 24/7 out of hours and end of life (EOL) community nursing care across the region. There is also a diagnosis lottery with good specialist nursing cover for children with cancer but with no such service for others. This strategic document sets out the need for change and the need to close the gap in services. The vision is underpinned by the principles set out in the Ambitions document (2015) and NICE Guidance 2016 (NG61).

The strategy aims to develop equitable palliative care across the region. It will involve CCGs and STPs working with provider services across a large geographical area to plan, coordinate and deliver services to a large population of babies, children and young people, as recommended in national guidance. The strategic document describes the current service provision and sets out how an equitable, high quality service can be achieved by collaboration and by putting the needs of children and families at the heart of the creative changes in the way services are funded and delivered.

## National Context

There has been an increase in national interest in children's end of life (EOL) care following a number of high profile cases in the media. The following are recent published reports relevant to children's palliative care:

**TfSL Commissioning report 2017**

**NICE guidelines NG61 2016**

**NHS Ambitions 2015**

**The NHS service specification (2013/14)**

**TfSL perinatal and children's pathway (2017)**

**The Government EOL choice review (2016)**

**NHSE&I Service Specification for children's palliative care (2020)**

These documents set out the standards that children and families should expect and the expectations upon commissioners and service providers. The recommendation lay the foundation of this strategy. There is an opportunity to develop children's palliative care nationally, regionally and locally and to promote equity and high quality services for all children reflecting the services available for adult palliative and EOL services. The Sustainability and Transformation Partnerships (STPs) have the responsibility to ensure equity of service provision for end of life care. Due to the low numbers of child deaths compared with adults, there is a case for regionally working to pool resources to develop services for children.

## Current Service Provision

There are currently 14 NHS trusts across the region providing children's community nursing. This cover is not 24/7 everywhere. There are six consultants providing palliative medicine across the region, two of whom are specialists at level 4. The tertiary centres do not have specialist palliative care services or teams other than for oncology diagnoses. The children's hospices provide differing services and differing levels of cover. Bereavement services are not provided for all child deaths across the whole region and there is a lack of psychological support for many families across the region.

East Anglia Children's Hospices (EACH) undertook a literature review regarding children and family views and most of the research identified provided the same themes throughout.

### What families want is:

- 1 point access and care coordinator
- Respite care
- High quality 24/7 nursing care when and where needed
- Support before a crisis occurs and crisis management
- Time out for 'normal family life'
- Transition services

### What children and young people want is:

- Chance to meet up with and talk to those with a similar diagnosis
- 24/7 medical advice
- Life plans not illness or end of life plans – coordination so all people have same plan
- Consistent care
- Psychologist advice
- Home care where possible

## Managed Clinical Network

The Network has developed into a Managed Clinical Network (MCN). This will ensure that there is clear and transparent governance structures in place and improve consistency in service provision across the region. The MCN will produce guidelines and pathways which ideally will be endorsed by the NHS trusts, the hospices and the community teams across the region. It is envisaged that each provider organisation designates a palliative care lead/ liaison representative to attend the quarterly network meetings.

The MCN is made up of five groups which meet quarterly:

- An Executive Committee which oversees strategic development and implementation and monitors progress
- A Clinical Forum which is an open group for any network member to attend. Membership of the Network is open to any health care professional with responsibility for babies, children or young people with a life limiting condition
- A Workforce and Education forum - also an open group for any network member to attend
- A non-medical prescribing group which meets regularly to discuss advances and developments in non-medical prescribing and provide a peer support function
- ECHO transition sub group



## The Purpose of YHPCPN

- To develop a regional strategy to improve provision of palliative care services for babies, children and young people
- To identify gaps and challenges in service provision and work towards filling these gaps
- To quality assure the provision of children's palliative care services
- Through the Managed Clinical Network, provide a sharing and supportive forum for professionals working in children's palliative care and contribute to the evidence base in this area
- Through the Education and Workforce Forum, facilitate training and workforce development in children's palliative care
- To explore and encourage cross boundary working and sharing of good practice and expertise
- To give children, young people and their families a voice and opportunity to influence palliative care services
- To establish effective links with relevant commissioning networks
- To represent Yorkshire and Humber children's palliative care nationally and lobby for change where it is needed

## Phases of development

### Phase 1:

To establish a managed clinical network for children's palliative care services in Yorkshire and the Humber with a medical and nursing lead for the region and with secured funding for the network coordinator. Where possible clinical guidelines will be shared across services and organisations for increased efficiency and to improve consistency of patient management as patients move between services.

### Phase 2:

To develop a hub and spoke model of delivering children's palliative care with an identified clinical lead for each hospital and hospice (14 NHS Trusts, 4 Children's Hospices) in Yorkshire and the Humber.

### Phase 3:

To work towards establishing a palliative medicine team in both Sheffield Children's Hospital and Leeds Children's Hospital as required in the NICE Guidance 2016. The development of 247 community nursing services for children across the region. Initially starting with pilots in each of the STP/ICS footprint areas.

### Phase 4:

To establish a 24/7 medical advice line for professionals in the region caring for children at end of life or with complex symptom management problems. This would initially be a pilot project requiring evaluation and therefore would necessitate the development of a Children's Palliative Care Register.

### Overview of the YHPCPN MCN:

