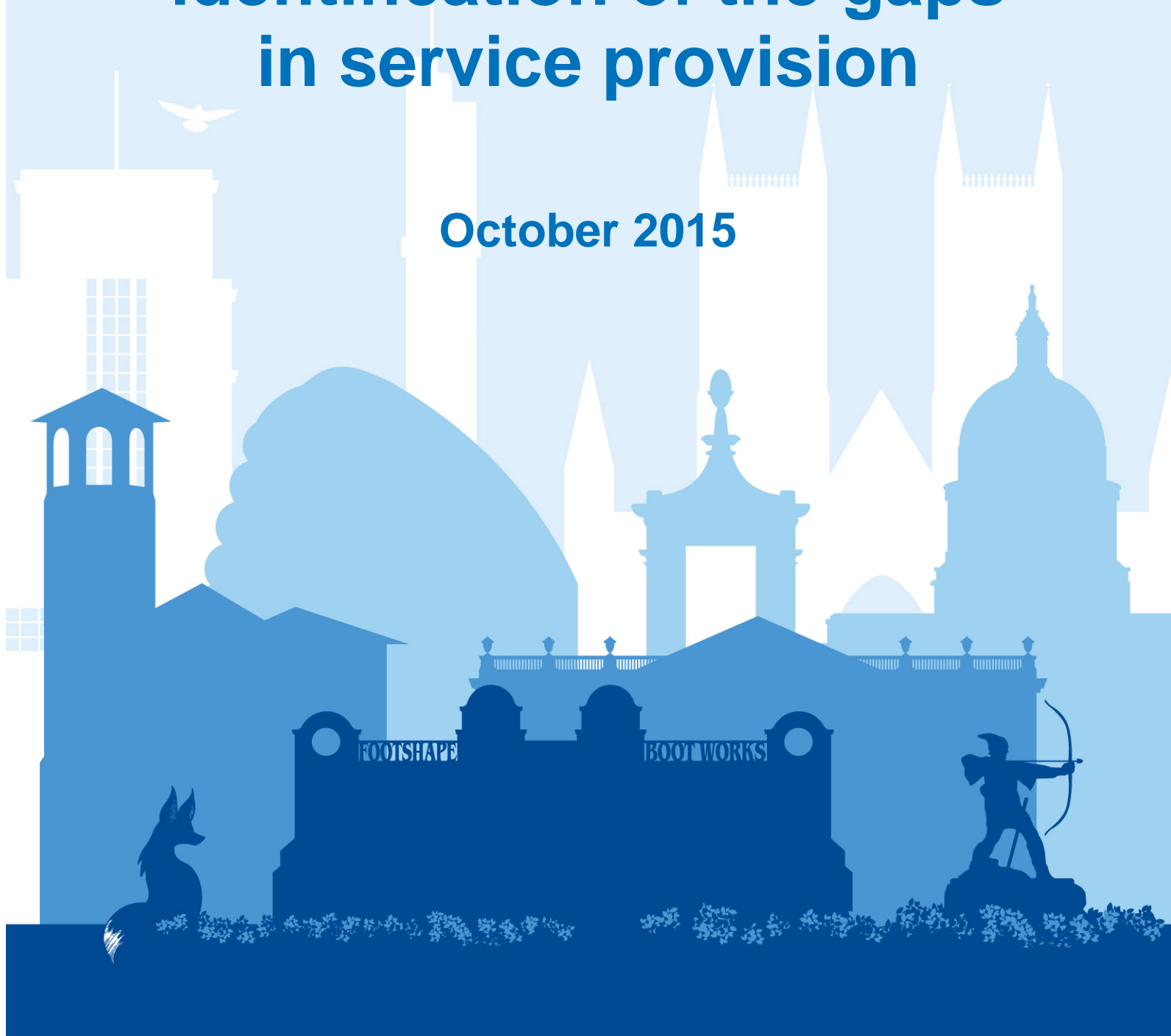


Report:

# Audit of children's palliative care services in the East Midlands and identification of the gaps in service provision

October 2015





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## i. Foreword

Sadly, some children and young people suffer from illness and disease that can shorten their lives. This can be acute and sudden, but for some, their condition can result in a gradual decline in their health and an increase in their health need and dependency, with death as an expected outcome. These children, young people and their families deserve care that is timely, and responsive to their developing and individual needs

There is a long history of good children's palliative care in East Midlands – the first mobile respite care service in England was established in Nottingham in the early 90s, and Leicester developed one of first Diana teams in the UK. Services for children with life limiting and life threatening conditions have developed in a number of different ways across the region.

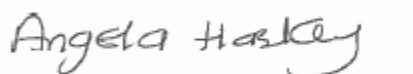
The East Midlands Children's Palliative Care Network was established ten years ago to enable services to work together to improve service delivery and support each other. This report has provided the network with an opportunity to review current practice, share the many examples of excellent care that is provided across the region and look for common solutions to areas that need collective improvement.

We have an obligation to work together. This is an opportunity to review how our area reflects best practice, clarify our strengths, and describe our pathways whilst acknowledging gaps in provision so that we can plan and inform commissioning to support service delivery. We hope this report provides us with a platform to do just that.

We would like to thank Dr Wolff, former Network Manager Sue Dryden and all the units for their contribution to this report.



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## ii. Executive Summary

There are increasing numbers of children and young people with life limiting and life threatening conditions living for longer in the community supported by technologies such as gastrostomies and home ventilation. Most of these children have severe neurodisabilities and neurodegenerative conditions and because of the complexity of their medical needs they often remain under the care of hospital-based specialist teams, sometimes without early discussions about palliative care treatment options and alternative places of care. These children tend to have frequent hospital admissions for intensive care and often die on intensive care units.

Children, young people and their families cannot have real choice regarding place of care and place of death unless discussions about the life threatening nature of their conditions are held in a timely way and they are introduced to high quality community teams who can offer expert and consistent care in the community.

This audit of children's palliative care services in the East Midlands began as a self-evaluation exercise by the provider members of the East Midlands Children's and Young People's Palliative Care Network. Further data collection and this report was then commissioned by the East Midlands Strategic Clinical Networks in order to identify gaps in provision and develop a strategy to ensure high quality and equitable services across the region.

Community paediatric palliative care services in the East Midlands are provided by the local children's community nursing teams, together with the Macmillan nurses for children with cancer. Some teams are managed within acute hospital trusts and all have close working relationships with the local hospital based services, in-reaching to support the discharge of children for end of life care in the community. Not all of the community nursing teams are specifically commissioned or funded to provide 24/7 end of life care and only two teams said this could be activated at any time. There is a particular gap in the south of Northamptonshire where currently there is no community nursing service offering end of life care at home. Some other teams are small and rely heavily on the goodwill of individual team members who give up their time at short notice to provide end of life care to their patients. Community nurses expressed the need for ongoing, practice based training regarding symptom management and communication skills.

Children and young people with life-limiting and life-threatening conditions and their families need coordinated support, often over many years and through several transitions. The audit found that the provision of multiagency care plans and reviews with an identified lead professional or key worker was generally lacking. In some areas a specialist family support service working closely with the children's community nursing team provides a key working service and is particularly helpful in the support of 'hard to reach' families from ethnic minority and deprived populations.

The medical support to the community children's nurses when they are providing end of life care in the community comes from the child's GP and paediatrician. The level of experience and confidence in this medical support is reported to be variable and some teams currently rely on medical support from the hospice. 24/7 specialist palliative care telephone advice would be helpful for the local teams but is not commissioned in the East Midlands.

There are only two commissioned paediatrician programmed activities for palliative care in the East Midlands and these provide a service for children living in Nottingham City and South Nottinghamshire only. Two other paediatricians in the region try to take the lead on children's palliative care in their local hospitals but have no time identified in their job descriptions to do it. There is generally a lack of specific policies, pathways and guidelines within the hospitals to identify and plan for children with LLCs and LTCs and therefore very little service evaluation or quality improvement. The current lack of specialist palliative care paediatrician resource in the region limits the training in palliative care that is being provided to the current work force at all levels and has implications for paediatric palliative care provision in the region in the future.

### iii. Summary of recommendations from the audit

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#### **Configuration of children's palliative care services:**

- Each organisation caring for children in the region should have an identified lead nurse for children's palliative care.
- Each locality should have an identified lead paediatrician for paediatric palliative care with 2 PAs per week and the skills to undertake the role, funded by local commissioners.
- There should be 2 WTE specialist palliative care paediatricians in the East Midlands working at paediatric palliative care competency level 4, funded through specialist commissioning.

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#### **Identification of all children and young people with palliative care needs in each service area:**

- There needs to be a wider use of specific tools which are already used by some teams to aid recognition and planning.
- Training and support for paediatricians to identify children and have discussions with families.
- Each of the community nursing teams should identify the children on their case load with life limiting conditions or long term conditions and identifying the 'phase of condition' using the palliative care currency definitions.

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#### **The paediatric palliative care pathway:**

##### ***Breaking the news:***

- There should be a lead nurse for children's palliative care in each organisation who can help ensure that an appropriately skilled nurse is available to support with breaking the news, and could also ensure there is adequate emotional support for nursing staff afterwards.
- There should be a lead paediatrician for palliative care in each organisation who can collect feedback from families and the supporting nurses to help individual doctors and the breaking the news process improve.

##### ***Planning for discharge:***

- All the district general hospitals in the region and particularly the tertiary units, Nottingham University Hospitals NHS Trust and University Hospitals of Leicester NHS Trust, should have specific discharge pathways both for children with complex health needs and also for the prompt but supported discharge of children with end of life care needs. The development and subsequent audit of these pathways should be led by a lead paediatrician for children's palliative care in each organisation.
- A continuously updated directory of each community nursing service in the region, with contact details should be maintained by the EMCYPPCN and shared regularly with each of the local leads for children's palliative care in each locality.
- The possibility of using the GP information systems which currently coordinate adult palliative care needs to be explored.
- Specific transport for a deteriorating child to leave hospital to have end of life care at home needs to be commissioned.

##### ***Coordinated assessment of care needs and multi-agency action plans:***

- There should be a specialist family support service working closely or as part of each children's community nursing team, who can provide a long term or intense key working role, particularly for 'hard to reach' groups such as those from ethnic minorities.
  - A community children's respiratory physiotherapy service should be available to all children with severe disability and life threatening respiratory problems across the region.
  - A survey of children and young people with life limiting and life threatening conditions and their families regarding their therapy needs and the provision across the region should be commissioned.
-

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**Recognition and planning for end of life care:**

- All areas should have a lead paediatrician in paediatric palliative care who is trained and experienced in recognising when a child is reaching the end stage of a life limiting condition and who is experienced in end of life care planning, who can support and train other local paediatricians to do the same.
- All the teams should use template documentation to ensure all the child's and family's choices are fully documented in a timely way and can be shared with all professionals in all settings.

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**End of life care in the community:**

- All the children's community nursing teams should be specifically commissioned and adequately funded to be able to provide 24/7 end of life care which can be activated at any time.
- There needs to be competent and confident medical support for the community nurses at all times including out of hours and weekends.

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**Care after death:**

- Explore the possibility of children's community nurses being trained and having policies in place to allow them to verify the death of a child in the community.
- All locality child bereavement services to be able to respond rapidly to the death of a baby in utero, neonate, child of any age, including sudden unexpected death: 24 hours per day, 7 days per week.
- Specialist child bereavement counselling services in all areas.
- All teams should have formal systems in place to collect feedback from bereaved parents and carers, at least annually, and to be able to use that feedback to improve the quality of the service.

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**Transition:**

- There needs to be an identified transitions lead for Sherwood Forest Hospitals.
- All trusts should adopt the East Midlands best practice guidelines for transition from children's to adult services.
- All trusts should adopt the Together For Short Lives (TFSL) recommendations in Stepping Up.
- Clinical commissioning groups should follow the recommendations in the TFSL transition guide.

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**Education, training and competency monitoring:**

- There needs to be an education and training subgroup of the EMCYPPCN to take forward the education and training needs of the workforce on a regional level.
- It is recommended that HEEM commission a children's palliative care degree module at Master's level with opportunities for practice based learning, in addition to the current basic level degree module.
- HEEM to commission an advanced communication skills course with 12 places per year for nurses and allied health professionals.

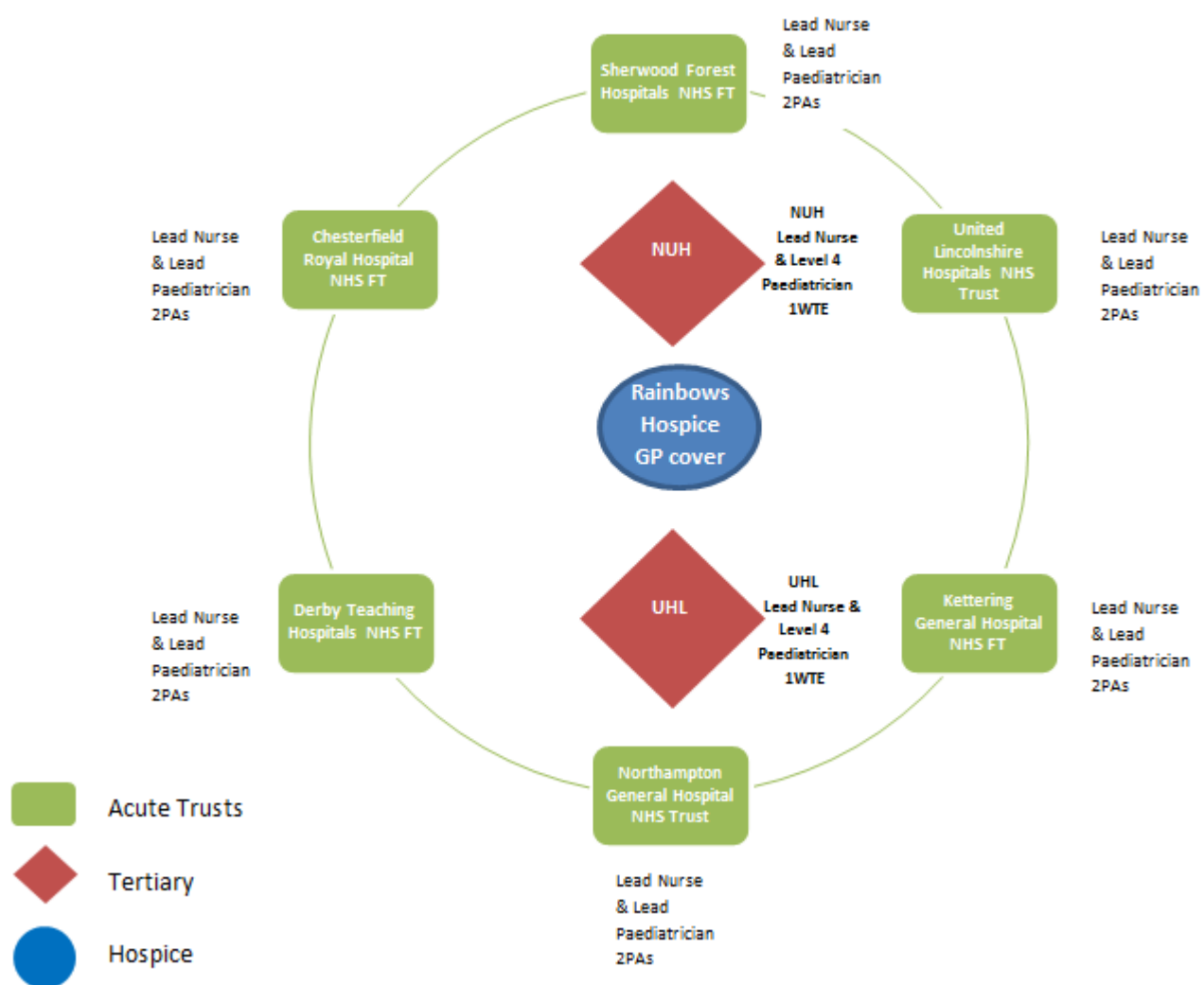


#### iv. Recommended configuration of children’s palliative care services for the East Midlands

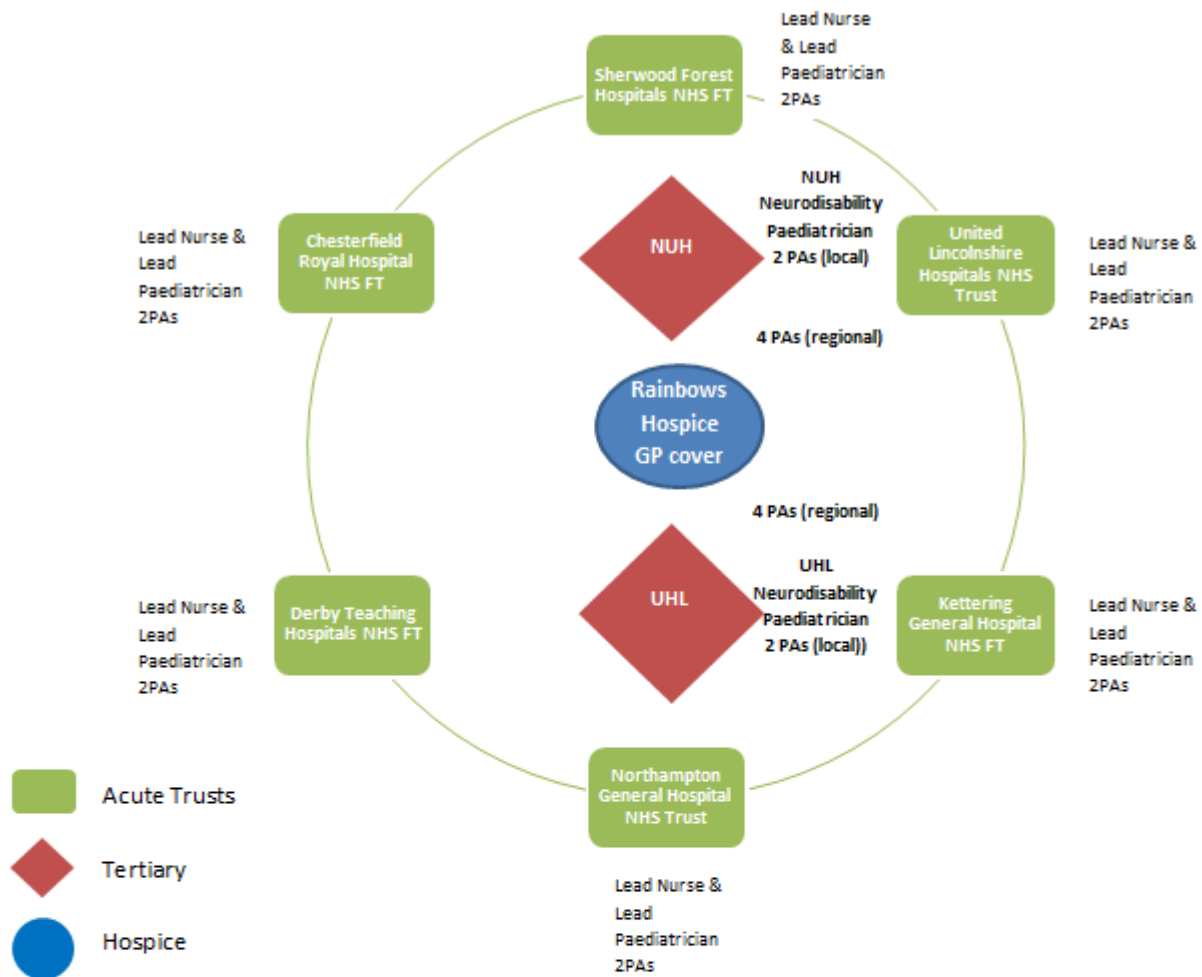
Children’s community nursing services covering the entire population and specifically commissioned to provide 24/7 end of life care in the community, which can be activated at any time.

Plus the following:

*Diagram to show the ideal model of care (copy of figure 9)*



*Interim model of care (copy of figure 10)*



**Provides 8 PAs for specialist palliative care paediatrician service at regional level**

	<b>NUH</b>	<b>UHL</b>
Teaching, training audit and research	1PA	1PA
Ward rounds intensive care units PICU & NICU / joint clinics oncology	1PA	1PA
Complex Cases and Joint clinics with locality lead paediatricians	1PA	1PA
Clinical admin. / Professional development	1PA	1PA

NUH - Nottingham University Hospitals NHS Trust

UHL - University Hospitals of Leicester

## **v. Actions for clinical commissioning groups**

As recommended in the National End of Life Care Programme - Commissioning tool kit<sup>35</sup> and the Together for Short Lives - Commissioning guidance 2015<sup>(36)</sup>

### **1. Build partnerships**

Clinical commissioning groups should commission paediatric palliative care services in partnership with local authorities to ensure an integrated service.

### **2. Analyse and plan**

- Get to know your local area's needs.
- Assess services and gaps.
- Agree quality outcome measures and incorporate into service specifications and contracts.
- Conduct user/carer consultations.
- Include children with life-limiting and life-threatening conditions in local joint strategic needs assessments and joint health and well-being strategies.
- Local groups of clinical commissioning groups should work together to assess demand and plan services effectively for these children who are relatively small in number but very costly for NHS resources.

### **3. Design pathways**

Children's palliative care is very different from adult palliative care. Most children with life limiting or life threatening conditions will have severe disability and they may live for many years, so the paediatric palliative care pathway needs to be integrated with local pathways for disabled children and children's continuing care.

- Build on existing provision.
- Consider user views.
- Consider how effectively services meet the needs of hard to reach groups.
- Consider mechanisms for information sharing.
- Ensure robust processes for hospital discharge and out of hours care.

### **4. Specify and procure**

- Commission a comprehensive local paediatric palliative care service including community children's nursing teams who can provide 24/7 end of life care, promptly, at any time.
- Specify the local paediatric medical support for the service, including identified paediatrician programmed activities for children's palliative care.

### **5. Deliver and improve**

Clinical commissioning groups should support paediatric palliative care services in collecting and analysing data on performance and outcomes, so that ongoing service evaluation can lead to improvements and innovations. Data collection should include numbers of children with life limiting and life threatening conditions locally, and numbers of children dying from LLC and LTC and where they died

Feedback from families should be collected in a structured way and used to improve services

## 1. Introduction

### Key messages:

- There are increasing numbers of children and young people with life limiting and life threatening conditions living for longer in the community.
- There is an increased prevalence in deprived and ethnic minority populations
- Approximately 75% of children with life limiting and life threatening conditions have congenital abnormalities and / or neurological conditions. They are likely to be receiving local services for children with severe disability.
- Life limiting and life threatening conditions are most frequent in children 0-5years, and the need for end of life care is highest in this age group.
- The numbers of young people with life limiting and life threatening conditions requiring transition and adult services are growing.

### 1.1 Definition and principles of paediatric palliative care

Palliative care for children is an active and total approach to care, from the point of diagnosis or recognition, throughout the child's life to death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement. (*Together for Short Lives* [www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk))

#### Families say they need:

- To feel in control
- To be treated with respect
- To be supported by trusted professionals - 24/7
- Care to be coordinated, and there to be continuity of people involved
- Their child to be comfortable
- To know that death, when it comes, was inevitable and at the right time
- To know that their child's life was important and had meaning

### 1.2 Together for Short Lives – Charter

Together for Short Lives is the leading UK charity supporting children and young people with life limiting and life threatening conditions and their families. The charter focuses on the types of information and support Together for Short Lives believes families should expect to receive. It emphasises the importance of choice for families, and encourages a joined up approach from all services and professionals involved in the care of children and families;

1. Every child and family member should be treated with respect and dignity.
2. The child and family should be offered an individual care and support package that is built around their unique needs.
3. A multi-disciplinary team should work together to support the family, and communicate with the child and family in an open and honest manner.

4. Children and families should always be listened to, and be encouraged to talk through their wishes and care choices.
5. At all stages of care, from diagnosis to death and bereavement, families should be provided with accurate and relevant information that they can understand.
6. Where possible, children should be cared for in the family's place of choice – in hospital, a hospice, or at home.
7. Emotional, psychological and spiritual support should be offered to the child, and those close to him or her.
8. Children and young people should be given the opportunity to access education and employment that is right for them.
9. The child and family's wishes concerning end of life care should be discussed and planned for well in advance.
10. Support and care should extend to all family members, friends and all those involved with the child.

[http://www.togetherforshortlives.org.uk/families/information\\_for\\_families/2456\\_together\\_for\\_short\\_lives\\_charter](http://www.togetherforshortlives.org.uk/families/information_for_families/2456_together_for_short_lives_charter)

### 1.3 The prevalence of children and young people with life limiting conditions

Fraser et al. (The Leeds study) published in 2011<sup>(1)</sup> estimated that there are over 40,000 children (0-19 years) living in England with a life limiting (LLC) or life threatening condition (LTC). This study found that the prevalence of this group of children and young people is increasing year on year; increasing from 25 per 10,000 population in 2001 to 32,000 per 10,000 population in 2010. It also found that children living with life limiting and life threatening conditions are particularly prevalent in ethnic minority groups (particularly those from South East Asia) and also in deprived populations.

**Estimated numbers of children (excluding neonates) requiring palliative care services** (Fraser et al 2011):

	Prevalence	Deaths per year
England	17,528	1787
Average strategic health authority	1,795	166

In neonates, overall paediatric palliative care need is not reported, but on average there are 2,109 neonatal deaths per year for causes likely to have required paediatric palliative care in the UK<sup>(2)</sup>.

For health care commissioners these will seem to be relatively small numbers, particularly when considering the number of deaths in adults per year. However these children often require a high level of NHS and social care resources at extremely high costs to local services. Also, the impact of their complex needs and death in childhood often has long term effects on the subsequent health and care needs of their family members.

Fraser et al. also estimated that there were 12,827 young adults, aged 18-25 years old, in England in 2010 who were living with a life limiting and life threatening condition, and their numbers are growing<sup>(3)</sup>.

## 1.4 Data from the West Midlands 'The Big Study' <sup>(4)</sup>

'The Big Study' [http://www.togetherforshortlives.org.uk/professionals/projects/project\\_one](http://www.togetherforshortlives.org.uk/professionals/projects/project_one) looked at the prevalence of children and young people needing palliative care services within the West Midlands area from July 2011 to March 2012 and was carried out by a large team of academics and clinicians lead by Together for Short Lives.

1,180 children and young people (excluding neonates) were identified who were living with LLC and LTC and 131 children (excluding neonates) were identified who had died between 13 and 24 months prior to the study time period.

Over 50 per cent of the children had either congenital and chromosomal disorders or static encephalopathy, for example, cerebral palsy. Approximately 75 per cent of the children are likely to be under the care of the local neurodisability teams.

The median age of the living children was 8 years and the median age of the children who had died was 3.5 years.

37 per cent of the population of children with LL and LTCs were from ethnic minority backgrounds compared with 15 -22 per cent of all children in the West Midlands having an ethnic minority background. The largest ethnic minority group was South Asian (27 per cent). In the Birmingham and Solihull cluster areas the proportion of children with LL and LTCs from South Asian ethnic minority groups was nearly half (47 per cent) whereas in West Mercia the proportion was only 6 per cent.

**Figure 1. Disease groupings of children (excluding neonates) n=1180, with life-limiting conditions known to services in West Midlands at end of April 2011**

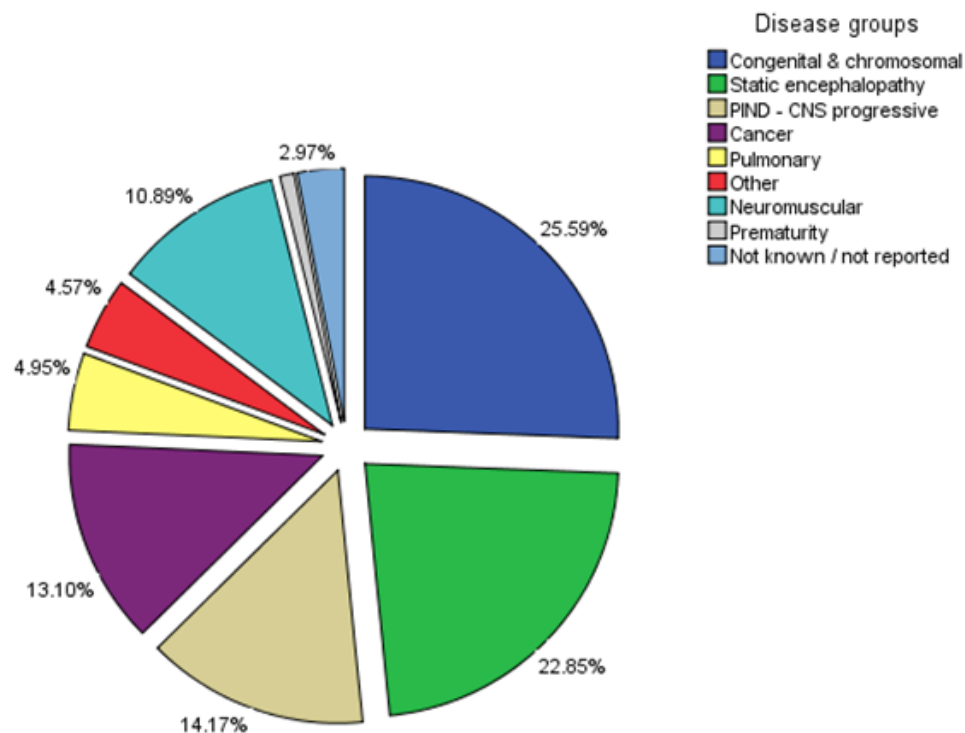


Figure 2. Disease groupings of 131 children (excluding neonates) who had died 13 to 24 months previously

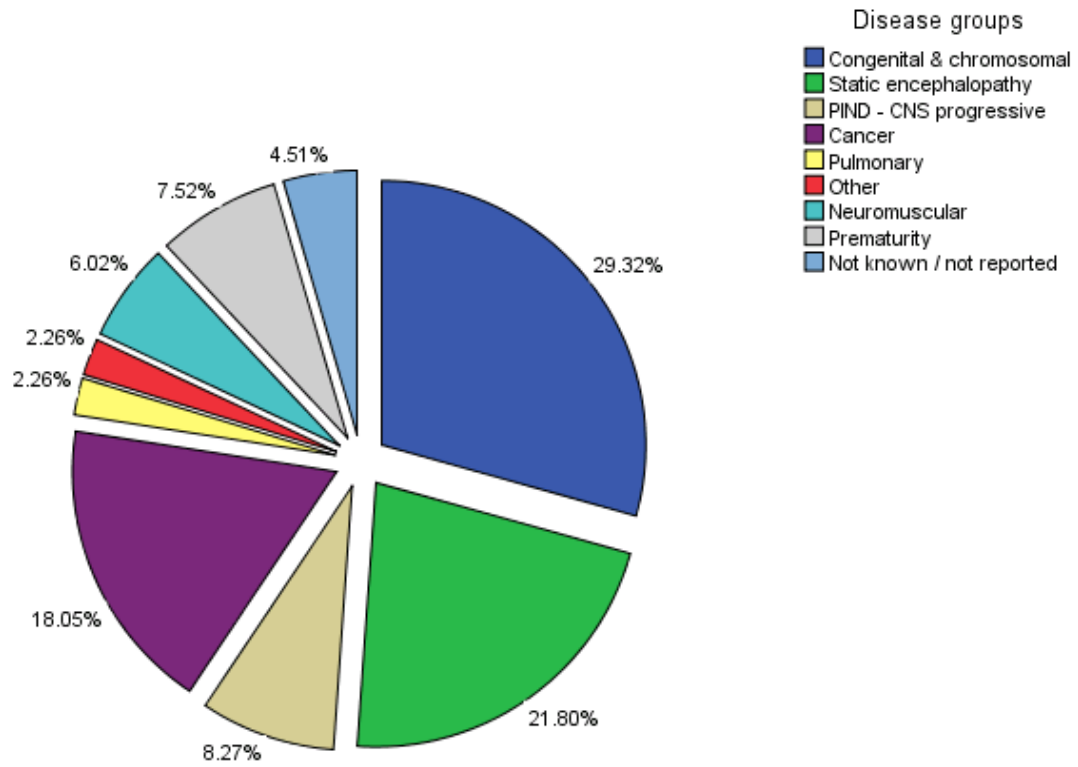
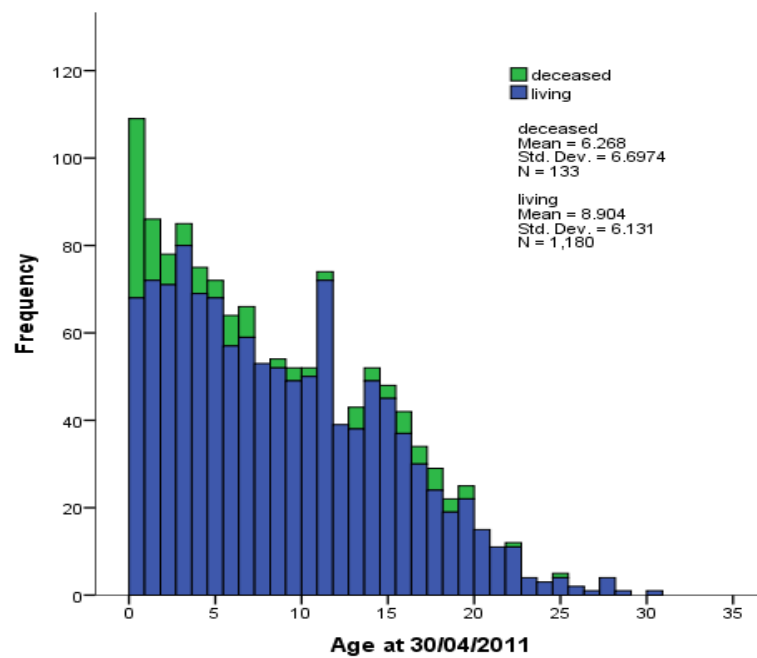


Figure 3. Age distribution of 1,313 children (excluding neonates) of whom 1,180 were living with life-limiting conditions (age is calculated at end of April 2011) and 133 who had died in previous year (age calculated at end April 2010).



## 1.5 Data from the East Midlands

### Geography and population of the East Midlands

There are over 1 million children and young people (aged 18 years and under) living in the East Midlands.

*Table 1. East Midlands child population by age and area*

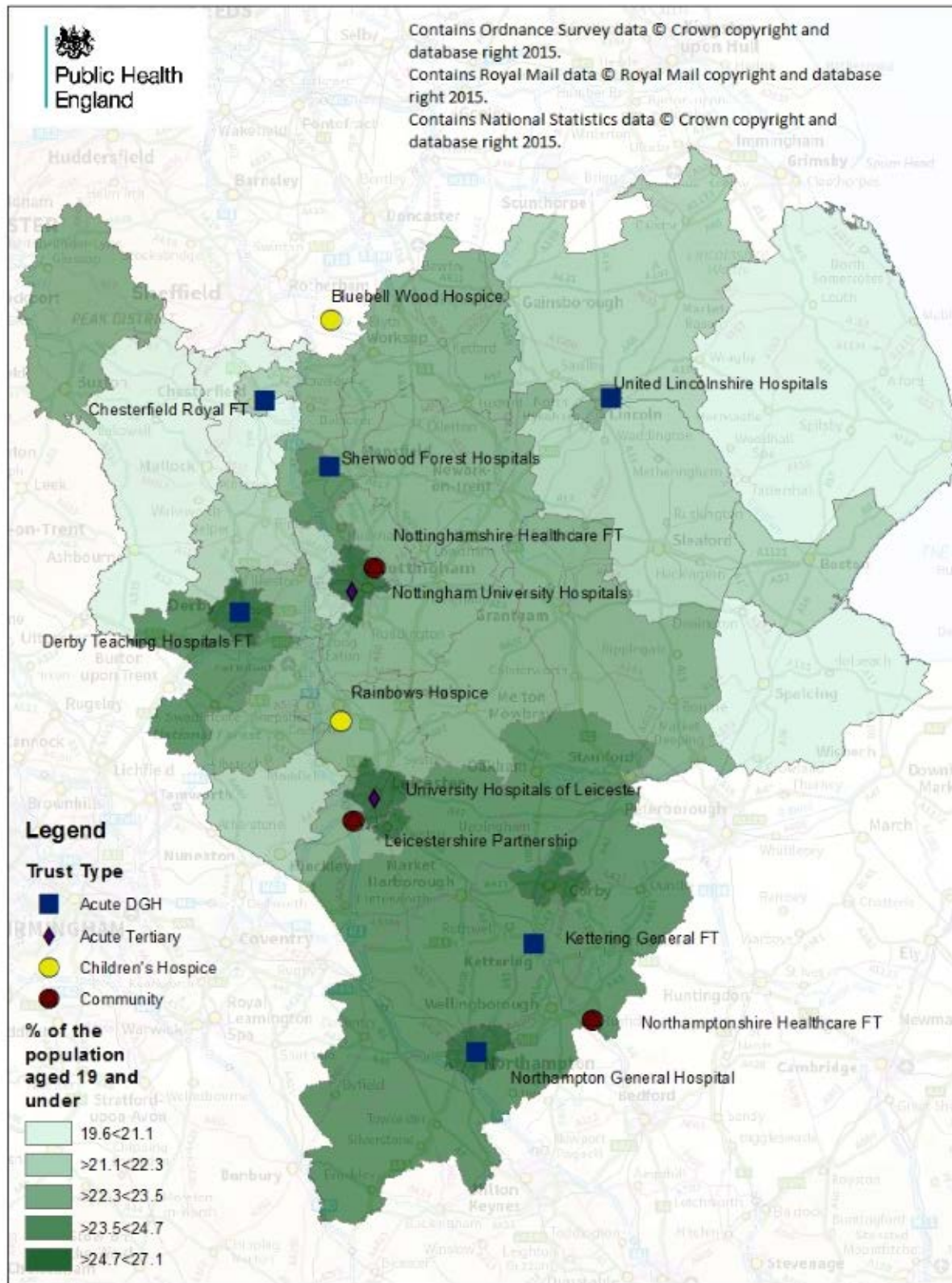
	Under 1	1 - 4	5 - 9	10 - 14	15 - 18	18 and Under
England	696,441	2,696,915	3,083,582	3,007,871	2,609,396	12,094,205
East Midlands	55,849	219,974	256,022	257,006	227,175	1,016,026
Derby	3,776	14,295	15,649	14,519	12,499	60,738
Derbyshire	8,396	33,749	41,205	43,380	38,699	165,429
Leicester	5,388	19,574	21,456	19,642	17,140	83,200
Leicestershire	7,100	29,437	36,342	37,231	33,034	143,144
Lincolnshire	7,966	30,851	35,964	38,947	34,784	148,512
Northamptonshire	9,370	37,722	43,091	41,513	34,899	166,595
Nottingham	4,412	15,977	17,115	15,621	14,726	67,851
Nottinghamshire	9,124	36,950	43,290	43,895	38,842	172,101
Rutland	317	1,419	1,910	2,258	2,552	8,456

The proportion of the population who are children in local areas differs across the region. The map in figure 5 shows the proportion of the population who are aged 16 years and under, by local authority. It can be seen from the map that the highest proportions of children in the population are in the cities of Leicester, Derby and Nottingham with the lowest proportion in Lincolnshire County. This may have an impact on the differing demand for child specific services in different areas.

(East Midlands Strategic Clinical Networks and Public Health England, Feb 2014)



Figure 4. Map showing children's palliative care services in the East Midlands



(Public Health England, August 2015)

## 1.6 Data from Nottingham and South Nottinghamshire

A data collection exercise was undertaken in the East Midlands in 2011 to ascertain all children with LLCs and LTCs who were known to community services. The data collection for the whole region was incomplete, however 428 children and young people (YP) <19 years (excluding neonates) with a LLC or a LTC condition and an NG post code were identified:

Age group	Under 1yr	1-4yrs	5-9yrs	11-15yrs	16+ yrs
Number of children & YP	9	183	92	93	51

An audit in Nottingham in 2014, studied local end of life care planning documentation and place of death<sup>(5)</sup>. This involved a case note review of children with life-shortening and life-threatening conditions, who died 'expected' deaths between 1 April 2012 and 31 September 2013, identified using the Nottingham Child Death Review Team database. The sample included 42 neonates and 32 children over 28 days old. Results:

- 33 (79 per cent) neonates and 29 (91 per cent) children had documented end of life plans.
- Children under oncology and community paediatrics teams had higher quality end of life plans.
- Seven (17 per cent) neonates and 17 (53 per cent) children (non-neonates) had a documented planned location of death, which was achieved in 20/24 (83 per cent) cases.
- When template documents were used as a framework, the quality and execution of plans was better.
- All 42 (100%) of the neonates died in hospital.

### Deaths reported to the Nottingham Child Death Review Team in 2014 (Excluding neonates)

Figure 5. Expected/unexpected deaths

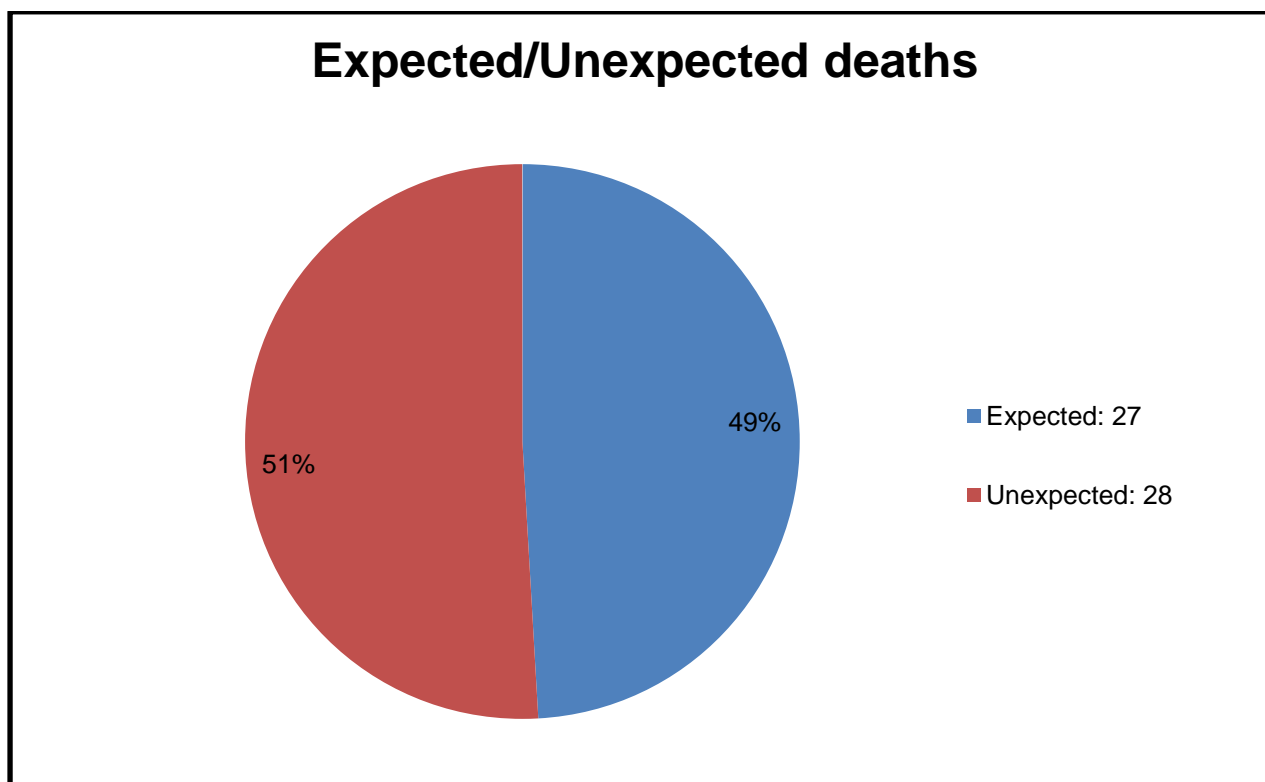


Figure 6. Number of children with LLC or LTC who had a Personal Resuscitation Plan at time of death

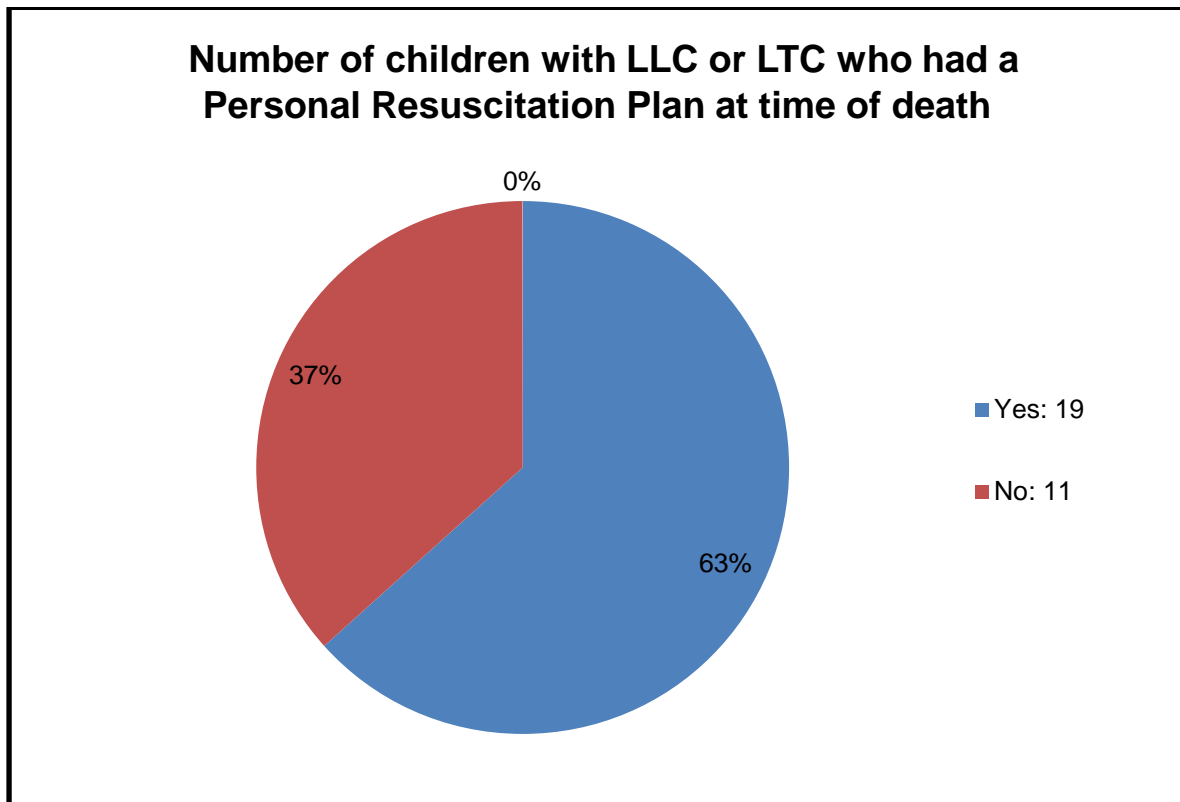
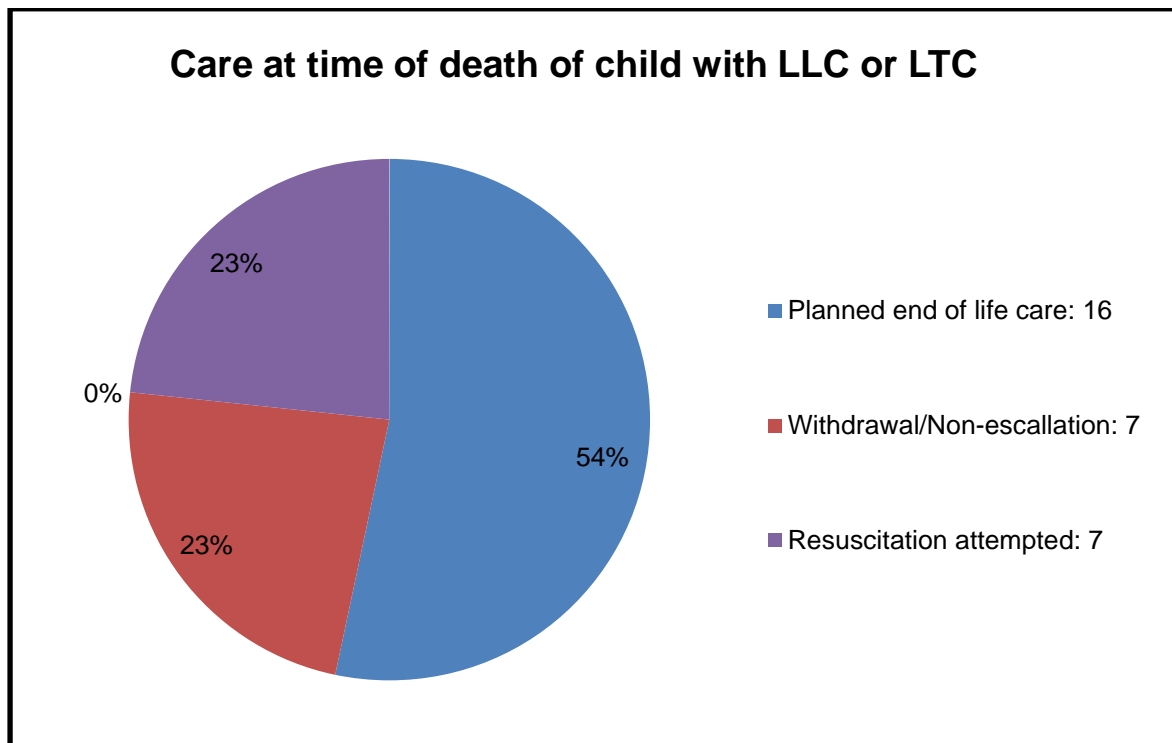


Figure 7. Care at the time of death of child with LLC or LTC





## Key messages from Nottingham and Leicester data

- All neonates who died in 2014 died on the neonatal units.
- Of the children who died with LLC and LTCs:
  - 1/3 died at home and 2/3 in hospital
  - 50% of those who died in hospital died on PICU
  - 50% of those who died were not having planned end of life care
  - Not all children dying an expected death had a personal resuscitation plan

The above suggests that there is room for improvement in services in the East Midlands in the following areas:

- To offer choice of place of death for neonates
- Early identification of children with life limiting and life threatening conditions
- Recognition that a child is coming to the end of life stage
- Planning for end of life care

## 2. East Midlands children's palliative care audit

### 2.1 Aim

To audit the paediatric palliative care (PPC) services in the East Midlands region against nationally recommended service standards.

### 2.2 Methods

Children's paediatric palliative care services were identified via the East Midlands Children's and Young Peoples' Palliative Care Network (EMCYPPCN) (Table 2).

Each team was sent the self-assessment tool from the Quality Standards for Children and Young People's Palliative Care developed in the West Midlands Paediatric Palliative Care Network<sup>(7)</sup> (Appendix 3). This was then followed up with an interview with lead clinicians for each paediatric palliative care service provider with additional questions using the self-assessment and evaluation tool from the Framework for the Delivery of Palliative for Children and Young People in Scotland<sup>(8)</sup> (Appendix 4). The audit also considered the recommendations in the NHS England Specialist Paediatric Palliative Care service specification (2013)<sup>(9)</sup> (Appendix 1).

**Table 2. Paediatric palliative care providers**

Trust/organisation	Type	Provides hospital or hospice based services	Provides a children's community nursing service	Provides a commissioned 24/7 end of life care service in the community
Bluebell Wood Hospice	Children's hospice	Yes	No	No
Chesterfield Royal Hospital FT	Acute trust	Yes	Yes	Yes
Derby Teaching Hospitals FT	Acute trust	Yes	Yes	No?
Kettering General Hospital FT	Acute trust	Yes	No	No
Leicester Partnership Trust	Community trust	Yes	Yes	Yes
Northamptonshire Healthcare Trust	Community trust	No	Yes	Yes
Northampton General Hospital Trust	Acute trust	Yes	No	No
Nottingham University Hospitals Trust	Acute trust	Yes	Yes	Yes
Nottinghamshire Healthcare Trust	Community trust	No	Yes	No
Rainbows Hospice	Children's hospice	Yes	No	No
Sherwood Forest Hospitals FT	Acute trust	Yes	Yes	No
United Lincolnshire Hospitals Trust	Acute trust	Yes	Yes	No?
University Hospitals Leicester Trust	Acute Trust	Yes	No	No

Each acute district general hospital and tertiary hospital provides medical and nursing care to children with LLC and LTCs.

There is one children's hospice sited within the region: Rainbows Children's Hospice in Loughborough. In addition, Bluebell Wood Children's Hospice in Doncaster (located just outside the region) provides hospice services to some of the northern areas particularly Chesterfield and Bassetlaw.

However the majority of children and young people with LLC and LTC conditions and their families live more than 20 miles from a children's hospice and most children's palliative care services outside hospital are provided by the local children's community nursing teams.

### 3. Audit Results and Recommendations

#### 3.1 Configuration of children's palliative care services

##### Quality standards:

These state that all services providing palliative care for children should have a nominated lead paediatrician and lead nurse responsible for ensuring the service meets all applicable quality standards and for liaison with the leads of other paediatric palliative care services within the local area. The lead paediatrician and lead nurse should have clinical involvement in paediatric palliative care.

The lead paediatrician is not one clinician providing direct care for all children with life limiting and life threatening conditions but rather a lead clinician to promote the service, develop pathways and policies, to lead on the audit and service development within that organisation, and to be a source of clinical expertise and advice to local clinicians and the local multiagency team.

NHS England Specialist Paediatric Palliative Care Service Specification <sup>(9)</sup> states that:

In addition to local core palliative care services, there also needs to be a consultant led multi professional specialist palliative care team, providing a clinical leadership role in planning, delivery and evaluation of children's palliative care services across a managed clinical network.

- a) It will be led by a medical consultant working at paediatric palliative care competency level 4; at least 1 WTE per 1-2 million population.
- b) The paediatric palliative care (PPC) specialist will be supported by a care team led by a senior nurse (level 7/8).
- c) Specialist palliative care services will be provided in partnership with local services, 24 hours a day, seven days a week according to the identified need of the child and family.
- d) Specialist palliative care telephone advice will be available to local network providers 24 hours a day, 7 days a week.
- e) Specialist palliative care telephone advice will be available to patients, parents and carers known to the service and will be available 24 hours a day, 7 days a week.

##### Audit findings:

Most of the children's community nursing teams have a nurse within the team with a lead role in paediatric palliative care and this is identified within their job description.

There are no identified lead nurses for paediatric palliative care in any of the hospitals.

There are very few paediatric palliative care doctor sessions in the region and most areas do not have an identified lead doctor for children's palliative care. (*table 3*).

There are only 2 funded paediatrician programmed activities in the East Midlands for palliative care.

There is no paediatrician with paediatric palliative care competency level 4 working in the East Midlands region.

There is GP on call doctor cover for inpatients in Rainbows hospice at level 3/4 competency, funded by the hospice.

The current lead GP for Rainbows, (a charity funded doctor working part time at level 4 competency) provides teaching, training, workshops, advice and support to staff caring for children across the region on



an *ad hoc* basis. This is not formally commissioned and is likely to discontinue when this doctor retires in the next few years.

**Table 3. Paediatric palliative care lead doctors in the East Midlands**

Trust/area	Lead doctor for paediatric palliative care identified	Commissioned paediatrician programmed activities	Paediatric palliative care competency level ( <i>appendix 2</i> )
Chesterfield Royal Hospital	No	0	
Derby Teaching Hospitals	No	0	
Kettering General Hospital	No	0	
Leicestershire Partnership	No	0	
Northampton General Hospital	Yes	0	Level 3
Nottingham University Hospitals	Yes	0.2 consultant paediatrician	Level 3
Rainbows Hospice	Yes	GP cover for the hospice	Level 3/4
Sherwood Forest Hospitals	Yes	0	Level 3
United Lincolnshire Hospitals	No	0	
University Hospitals Leicester	No	0	

### Recommendations:

Each organisation whether community or hospital trust caring for children in the region should have an identified lead nurse for children’s palliative care, with the role being specifically identified in his or her job description.

Each locality should have an identified lead paediatrician for paediatric palliative care, who is trained to competency level 3 (*Appendix 2*) and has two specifically commissioned programmed activities per week in their job plan to perform this role. Each programmed activity is a 4 hour funded doctor session.

In Nottingham, a community neurodisability paediatrician is commissioned to provide one programmed activity per week for clinical care of children with life limiting and life threatening conditions and one programmed activity per week to provide support to the local community children’s palliative care team and for service development, audit and teaching.

This could be developed and formalised within the job plans of other local paediatricians either community or hospital based, but ideally those trained and working in neurodisability as the majority of children with LLC and LTCs have neurodisabilities (*figures 2 and 3*).

However there will be training needs for these paediatricians to be able to work at paediatric palliative care competency level 3. Also, there is the need for additional doctor resource funded by local clinical commissioning groups to ensure that these children with very high level and complex care needs can be seen in:

1. a specific local clinic with extended appointment times to allow longer consultations.
2. other settings including home
3. joint clinics with the regional specialist PPC consultant (e.g. 3-4 joint clinics per year)

There also needs to be doctor time to lead local palliative care team meetings to review cases, and to support nurses with ethical dilemmas, emergency healthcare plans and personal resuscitation plans, end of life care planning and anticipatory prescribing to prevent unnecessary hospital admissions.

Another key function would be to support pathway development, teaching, audit and service improvement locally.

According to the NHS England Service Specification <sup>(9)</sup> there should be, in addition to the above local core services, at least two whole time equivalent (WTE) paediatricians in the East Midlands working at paediatric palliative care competency level 4, to provide highly specialist care to a small number of extremely complex children and also clinical advice and support to the teams across the regional network. These posts could be based in the two tertiary units: one in Nottingham University Hospitals (NUH) and one in United Hospitals Leicester (UHL) to provide:

1. Consultations regarding acutely ill children on the neonatal and paediatric intensive care units in both regional centres to support the early availability of paediatric palliative care and choice for families of place of care other than hospital.
2. Joint clinics with neurologists and oncologists at both centres.
3. Joint symptom management clinics with each of the locality based lead paediatricians for palliative care, as above.
4. Consultations regarding complex symptom management.

These regional specialist paediatricians in palliative care (PPC) would also lead on teaching, training, service development and evaluation, audit and research across the region.

Together with the locality lead paediatricians for paediatric palliative care they could support a rota to provide 24 hour specialist paediatric palliative care medical support to the local providers.

Funding for these two specialist PPC posts plus the specialist palliative care nursing resource to support them should come from specialist commissioners.

Figure 9 shows a diagram of the ideal service for the East Midlands according to the nationally recommended service standards. However it is likely that there will need to be a stepwise development of services towards this ideal and the service configuration in figure 10 is suggested as an interim step.

#### **Training local paediatricians in paediatric palliative care and succession planning:**

The lack of specialty trained paediatrician resource for paediatric palliative care in the East Midlands region is concerning; not only regarding the current provision of services but particularly for future service planning.

Current services are reliant on good will and two individual doctors who are both likely to retire within the next five years.

There are now Royal College of Paediatric and Child Health (RCPCH) recognised training and accreditation programmes for specialist palliative care paediatricians and also for paediatricians with a special interest in palliative care <sup>(10, 11, and 12)</sup>.

Formal postgraduate paediatric palliative care training for doctors in this region cannot be offered without additional doctor resource at paediatric palliative care competency level 4, for dedicated teaching time. Therefore, as the current doctors in Nottingham and Rainbows retire there will be no local trainees in paediatric palliative care to replace them.

### **3.2 Identification of all children and young people with palliative care needs in each service area**

#### **Quality standards:**

Identification of children with LLC and LTCs as early as possible allows more time for information sharing, discussions about best options of care, and planning for end of life care, including the development of emergency healthcare plans and personal resuscitation plans. This empowers families and gives real choice about their care through the journey of living with a LLC or LTC and the choice around end of life care, particularly place of care when dying.

Identification of the local population of children with palliative care needs and the increasing numbers provides data to support service planning both for children's services and also for services for young adults at transition.

**Audit findings:**

There is no live comprehensive paediatric palliative care database in the East Midlands region.

NUH are currently initiating a template for the child's electronic record which will support the early identification of children with LLC or LTCs and the prompt offering to families of paediatric palliative care services and will also support audit and service evaluation.

Other hospital services in the region currently have no systems for flagging children as having a LLC or LTCs and no specific paediatric palliative care pathways.

Each of the children's community nursing teams have their own individual case load registers, however children are not necessarily identified on the register as having a LLC or LTC (although one or two teams have started to do this), and children are not currently identified by phase of illness.

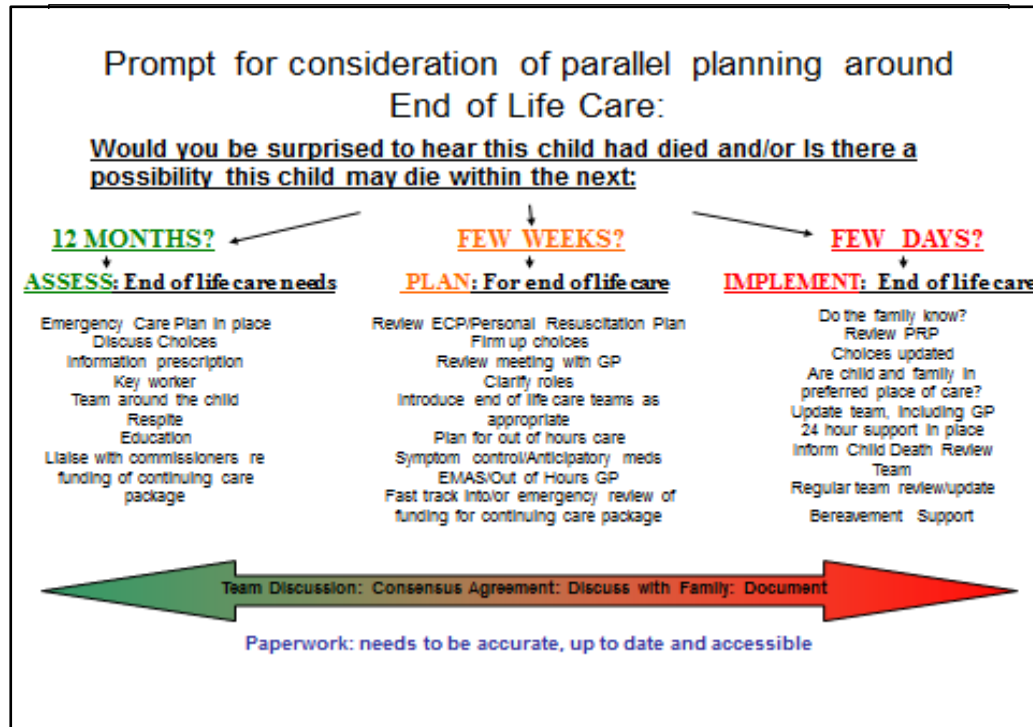
Not all children with LLC and LTCs needing support in the community will be known to the children's community nursing teams. For example, children and young people with neuromuscular conditions may have no nursing needs until late in their condition.

Children and young people under 18 years are not entered on GP registers for end of life care. There is however data regarding children who have died via the local child death review registers.

**Recommendations:**

- Most children with a LLC or LTC will be diagnosed by a hospital based paediatrician. The majority will be diagnosed whilst under the care of a neonatologist, neurologist, neurodisability paediatrician or a paediatric oncologist.
- Recognising that a child has a LLC or LTC and sharing that news with parents is very difficult for paediatricians. There is always uncertainty and the temptation to put off difficult conversations in the hope that things may become more certain. However delay in information sharing can adversely affect the choices and empowerment of families. Also, the lack of data about these children hampers service planning.
- The following tools and systems can be helpful and should be adopted:
  - Emergency healthcare plans <sup>(13)</sup>
  - Personal resuscitation plans <sup>(14, 15)</sup>
  - The Surprise Question <sup>(16)</sup>
  - The Hain's Directory <sup>(17)</sup>
  - Prompts for parallel planning <sup>(18)</sup>

The following prompt is used in NUH:



There needs to be a lead paediatrician for paediatric palliative care in each hospital (see recommendations in section 1 above) who can support paediatricians directly and also develop pathways and data collection systems so that children with LLC and LTCs are recognised promptly and information shared with families and other services (such as the most appropriate community nursing team) in a more timely way.

Each of the community nursing teams need to move towards ‘flagging’ children on their case load who have a diagnosis of a LLC or LTC using The Hain’s Directory and identifying the ‘phase of condition’ using the palliative care currency definitions <sup>(19)</sup> (table4).

The development of the palliative care currency into the palliative care tariff is likely to drive improvement in standardised data collection.

**Table 4. Nationally proposed palliative care currency units <sup>(19)</sup>**

Children’s hospital or hospice inpatient	Children’s Community Services
CW_1 <1yr	CC_1 Stable, physical severity low
CW_2 1-4yr	CC_2 Stable, severity high
CW_3 5-9yr stable	CC_3 Unstable <1
CW_4 5-9yr unstable	CC_4 Unstable 1-4
CW_5 5-9yr deteriorating/dying	CC_5 Unstable 5-9
CW_6 10+ stable	CC_6 Unstable 10+
CW_7 10+ unstable	CC_7 Deteriorating <1
CW_8 10+ deteriorating/dying	CC_8 Deteriorating 1-4
	CC_9 Deteriorating 5-9
	CC_10 Deteriorating 10+
	CC_11 Dying 0-9
	CC_12 Dying 10+

## 3.3 The paediatric palliative care pathway

### 3.3.1 *Breaking the news*

#### **Quality standards:**

Every family should receive the news of their child's diagnosis in a face-to-face discussion in privacy and should be treated with respect, honesty and sensitivity.

It is recommended that all providers have trained staff and policies in place to support breaking the news in an appropriate way which include the following:

- Private settings available.
- Facilities for face to face discussion with an interpreter if necessary.
- Appropriate generic and specific written materials for parents and children.

#### **Audit findings:**

Clinicians said that there are difficulties finding places for privacy on several of the inpatient units. All providers can access interpreters or use a language line. However, the latter can be unsatisfactory when having very difficult conversations.

All providers report that breaking the news policies are in place, however, feedback from some families and also some nurses suggests that many paediatricians are not following the recommended standards.

Community nurses are offering to support paediatricians with these difficult conversations, but they are not always involved at this early stage.

#### **Recommendations:**

Breaking the news is a process, not a 'one off' event. It requires paediatricians who have knowledge, experience, time and empathy. When this first part of the patient pathway goes badly, it can have a devastating effect on the rest of the patient journey. Parents can be left feeling shocked, alone and unsupported. Then they may not engage and work in partnership with services.

Whilst paediatricians should have the knowledge and should be able to make the time to do this well, they have varying levels of experience and empathy. Doctors should not be doing this alone. They should always have the support of an experienced nurse or specialist family support worker who can help the parents/carers/child to express their views, feelings and expectations and also provide ongoing emotional and practical support to the child and family.

- **There should be a lead nurse for children's palliative care** in each organisation who can help ensure that an appropriately skilled nurse is available to support with breaking the news, and could also ensure there is adequate emotional support for nursing staff afterwards.
- **There should be a lead paediatrician for palliative care** in each organisation who can collect feedback from families and the supporting nurses to help individual doctors and the breaking the news process improve.

### 3.3.2 *Planning for discharge*

#### **Quality standards:**

Most children with LLC and LTC are diagnosed in the hospital setting. Their prognosis may vary from many years living with a LLC to the situation where the child is going to die within a few days.

Quality standards require that every child and family diagnosed with palliative care needs in the hospital setting should have an agreed discharge plan that should be communicated to the community services

prior to discharge and all services need to be in place before the child is discharged including families and carers trained, essential resources being available and arrangements made for regular review of the care plans.

#### **Audit findings:**

In general the community children's nursing teams providing children's palliative care across the East Midlands are involved prior to the discharge of a child with end of life care needs, and the local community nurse will 'in-reach' to the ward to facilitate the discharge.

There is generally a lack of specific discharge planning pathways and procedures for children with complex needs/LLC and LTCs/end of life care needs within the hospital settings across the region. In particular professional suggest that communication between the tertiary centres, UHL and NUH, and the more distant community nursing teams needs to improve.

It is rare for GPs to be involved prior to the discharge of a child or young person, however, they are always informed by hospital teams and often involved after the discharge at the instigation of the community nursing services.

Transport for a deteriorating child or neonate to be able to leave hospital to have end of life care in their own home is currently a gap. East Midlands Ambulance Service are commissioned to provide a non-urgent ambulance within a 4 hour time period, but in practice a child can be waiting all night for an ambulance to be available and the window of opportunity to move the child out of hospital for end of life care may be lost. Rainbows hospice has recently started to provide from charity funds a specific transport service for a deteriorating child to be able to travel from hospital to the hospice.

#### **Recommendations:**

- All the district general hospitals in the region and particularly the tertiary units, NUH and UHL, should have specific discharge pathways both for children with complex health needs and also for the prompt but supported discharge of children with end of life care needs. The development and subsequent audit of these pathways should be led by a lead paediatrician for children's palliative care in each organisation.
- A continuously updated directory of each community nursing service in the region, with contact details should be maintained by the EMCYPPCN and shared regularly with each of the local leads for children's palliative care in each locality.
- The possibility of using the GP information systems which currently coordinate adult palliative care needs to be explored.
- Specific transport for a deteriorating child to leave hospital to have end of life care at home needs to be commissioned. There are some good examples of such services e.g. the Embrace system provides a highly specialised, 24/7 transport service for critically ill infants and children. It is provided in the Yorkshire region by Sheffield Children's NHS Foundation Trust<sup>(20)</sup>.

### **3.3.3 Coordinated assessment of care needs and multi-agency action plans**

#### **Quality standards:**

Every child and family should receive a multi-agency assessment of their palliative care needs and have a multi-agency care plan agreed with them that identifies a key worker for the family and provides coordinated care and support to meet those needs.

#### **Audit findings:**

- *Is a lead professional/key worker always identified for each child or young person?* **No.**

A key worker is more likely to be formally named and known as such to the family if the child has cancer or complex neurodisability with high level nursing needs, in which case the community children's nurse is often the identified key worker.

- *Does every child or young person have a multi-agency care plan agreed and regularly reviewed?* **No.** All children have healthcare plans but most children are still having reviews by different agencies separately. Some teams said that the Education, Health and Care Planning process may improve coordination for some children and young people in the future.
- *Is every child or young person and their family given choices about the care they receive?* **Yes.** Every team said they discuss choices about care, including place of care, but documentation of these discussions and the choices made is very variable and formal family held 'Choices' documents are rarely used.
- *Is feedback from the child or young person and their families collected and responded to regularly?* Most teams said they do this informally, and also use the 'Friends and Family Test'.
- *Is there a range of short breaks, including sitting services available?* **Yes.**
- *Are specialist family support workers and link workers for black and ethnic minorities available?* **In some teams only** (table 5).

**Table 5. Specialist family support workers**

Trust/organisation	Specialist family support service exists?
Chesterfield Royal Hospital	No
Derby Teaching Hospitals	No
Leicestershire Partnership	Yes
Northamptonshire -North/South	No
Nottingham University Hospital	Yes
Rainbows Hospice	Yes
Sherwood Forest Hospitals	No
United Lincolnshire Hospitals	Yes

**Recommendations:**

- There is a higher prevalence of children with life limiting and life threatening conditions amongst black and ethnic minority populations and in deprived populations<sup>(1,4)</sup>. These children are hard to reach and have a lower rate of uptake of palliative care services and home death<sup>(21)</sup>. Population projections suggest that the numbers and proportions of people from black, Asian and minority ethnic (BAME) groups will continue to increase in the UK.
- There should be a specialist family support service working closely or as part of each children's community nursing team, who can provide the intense key working role which these hard to reach families often need. There are examples of this service being commissioned from third sector providers (Appendix 5). A useful guide to developing key working services has been commissioned and made available by the National Children's Bureau<sup>(22)</sup>.

**Therapy**

The availability of physiotherapy, occupational therapy, speech and language therapy, play therapy and psychological support for children with LLC and LTCs varies enormously across the region and is difficult to specifically quantify. It may be easier to identify the unmet therapy needs for this client group by survey of children and young people with life limiting conditions and their families.

### **Children's community respiratory physiotherapy services**

An innovative children's community respiratory physiotherapy service is available in Nottingham and Nottinghamshire provided by NUH and also recently in Leicestershire. These two services support children with severe disability and life threatening respiratory problems, providing regular chest clearance programmes and a rapid response in an acute deterioration in order to prevent hospital admissions. Service evaluation shows very high levels of user satisfaction, reduced hospital admissions and significant cost savings, allowing the services to more than pay for themselves<sup>(23)</sup>.

#### **Recommendations:**

- A community children's respiratory physiotherapy service should be available to all children with severe disability and life threatening respiratory problems across the region. The current services benefit from close working with the regional respiratory paediatric services based in NUH and UHL. A suggested model would be for other local clinical commissioning groups to commission the service as an outreach from the current providers in Nottingham and Leicester.
- A survey of children and young people with life limiting and life threatening conditions and their families regarding their therapy needs and the provision across the region should be commissioned.

### **3.3.4 Recognition and planning for end of life care**

#### **Quality standards**

Every child and young person should be supported to decide on an end of life plan including choice of place of care and place of death once the end of life stage is recognised.

Recognition of the end of life stage is difficult in children with LLC and LTCs, and is particularly difficult for children with long term neurological problems who may deteriorate several times to the point of near death and then recover, only to deteriorate again in a few weeks. There needs to be parallel planning, with end of life plans in place 'just in case' the deterioration in a child's condition becomes the final phase of their life. All children at risk of a life threatening emergency should have emergency healthcare plans and resuscitation plans in place and documentation of their own and their families' choices around end of life care. This requires staff in all those teams caring for children who may have a life threatening event to have the skills and time to develop these plans and have difficult conversations with families and the children themselves. It also requires the early introduction of the community nursing team as children and families will only choose to stay home for end of life care if they get to know and trust the community team who will be looking after them.

#### **Audit findings:**

The fact that so many children with LLC and LTCs are dying on paediatric intensive care units (figure 8) and only 50-60% of children dying an expected death have personal resuscitation plans (figure 6) suggests that recognition and planning for end of life care in the region can be improved.

#### **Choices documentation**

Once children or young people and their families are known to the community nursing teams they are supported to make end of life care choices. However the formal documentation and sharing of the choices made by the child and family is variable. A few teams use family held 'Wishes and Choices' documents to record the planned place of death and plans for care of the body after death, funeral arrangements, and discussions regarding tissue donation.

For children in hospital, choice of place of care may be limited by time, availability of nursing support in the community, and availability of transport for a critically ill child to leave hospital.

Most areas have a community nursing team which can provide 24 hour support for end of life care. For some this service needs to be 'activated' within normal working hours, Monday to Friday. Teams that



routinely provide 24 hour on call service such as the Chesterfield team can respond promptly to deterioration in any child on their case load even if this occurs out of hours or at the weekend.

### **Symptom management plans**

In the community, each child will have a personal anticipatory symptom control plan in place which is reviewed regularly by the community nursing team and the supporting doctor who may be the GP or the local paediatrician or both. 24 hour symptom control is available in hospital depending on the expertise of the hospital team.

### **Pharmacy services**

The community nursing teams reported that they have excellent pharmacy support from their local hospital pharmacists to support the development of the anticipatory symptom control plans.

### **Resuscitation plans**

All the providers have systems for recording resuscitation decisions. All the community providers of children's palliative care across the region use the East Midlands Emergency Healthcare/Personal Resuscitation Plan (14) to document the medical plans for an acute or gradual deterioration and the resuscitation plan for each child.

### **Recommendations:**

- All areas should have a lead paediatrician in paediatric palliative care who is trained and experienced in recognising when a child is reaching the end stage of a life limiting condition and who is experienced in end of life care planning, who can support and train other local paediatricians to do the same.
- All the teams should use template documentation to ensure all the child's and family's choices are fully documented in a timely way and can be shared with all professionals in all settings.

### **3.3.5 End of life care in the community**

Quality standards for end of life care in the community include a daily visit from a trusted professional, 24/7 home visiting support from the end of life care nursing service, specialist palliative care telephone advice available 24/7, a lead doctor who reviews the care plans regularly (24- 48 hourly), the potential for parallel planning and support if the child doesn't die and anticipation of practical issues after death including notification of the coroner and provision for the verification and certification of death.

### **24 hour home visiting end of life care nursing service**

Only three out of seven of the community children's nursing services are specifically commissioned to provide 24/7 end of life care. However most of the teams say they do provide a 24/7 on call end of life care service. The ability of some teams to respond rapidly and flexibly is compromised by the lack of nursing resource. For some teams the end of life care service has to be requested / activated in normal working hours, Monday to Friday, but once activated they will provide 24 hour face to face nursing support. For several teams there is no pre-arranged rota and an on call service is provided in an *ad hoc* way largely through the good will of the community nurses, who put themselves on call to support their patients (Table 6).

### **The regular review of care plans/symptom management plans in the community by a lead doctor**

In all areas, the GP of the child having end of life care is encouraged to provide home visits often jointly with the community children's nurses, however, most GPs need the support of the child's paediatrician to manage a dying child and in most cases the community nurses will develop the care plans and symptom management plans with the child's paediatrician. For children with cancer there is ongoing support from the paediatric oncologists or doctors with special interest in oncology. Also there are paediatric Macmillan /outreach oncology nurses based in Leicester, Lincolnshire, Northampton and Nottingham providing cover for the region. Some of the children's community nursing teams rely on the hospice doctors for advice regarding care plans, symptom management and prescribing for children dying at home, although this is

not formally commissioned. The neurodisability paediatricians in Nottinghamshire provide out of hours support including home visits to children with end of life care needs.

### Specialist palliative care telephone advice

Community nurses report the occasional need for specialist palliative care medical support out of hours particularly when there are unexpected symptoms or the rapid escalation of strong analgesia is required. Several teams said they phone the hospice for advice 'out of hours', however, the provision of 24 hour specialist paediatric palliative care telephone advice is not formally commissioned.

**Table 6. Paediatric end of life care on-call services in the community**

Trust	Area covered	24/7 on call end of life care service is specifically commissioned	24/7 on call end of life care service is provided	WTE nurses contributing to the end of life service	Number children supported to die at home in 2014	Estimated child deaths from LLC/LTC per year
Chesterfield Royal	North Derbyshire	Yes	Can be activated at any time	4.8	2	37
Derby Teaching Hospitals	South Derbyshire	No	<i>Ad hoc</i>	4	4	
Leicestershire Partnership	Leicester and Leicestershire	Yes	Can be activated Monday to Friday	14	3	37
Northamptonshire Healthcare	Northamptonshire North	Yes	Can be activated at any time	9	0	27
	Northampton South	?	Not available	0	0	
Nottingham University hospitals	Nottingham and Nottinghamshire	Yes	Can be activated at any time	13.7	9	39
United Lincolnshire Hospitals	Lincolnshire	No	<i>Ad hoc</i>	12.45	6	24

### Rainbows children's hospice

Rainbows children's hospice in Loughborough provides a 24/7 inpatient nursing support for children accessing the hospice and there is a doctor on call to support the nurses on site and the children who are in-patients at Rainbows. The Rainbows team also provide a telephone advice service to families if their child is a regular user of the hospice. The doctors providing support for Rainbows will give telephone advice to a professional; however this is not formally commissioned. The lead GP for Rainbows provides *ad hoc* teaching and training workshops and support to professionals across the East Midlands region although this is not formally commissioned.

### Recommendations:

- All the children's community nursing teams should be specifically commissioned and adequately funded to be able to provide 24/7 end of life care which can be activated at any time.

- There needs to be competent and confident medical support for the community nurses at all times including out of hours and weekends. Systems for anticipatory care planning and local medical support could be improved by having a lead paediatrician for children's palliative care in each area.
- 24/7 specialist paediatric palliative care telephone advice to all the local teams could be provided if the ideal model suggested in section 1, above was commissioned (figures 10 and 11).

### 3.3.6 Care after death

#### Quality Standards:

Following the death of a child or young person every family should be allowed time and privacy with their child. Bereavement support should be offered for as long as the family requires this and should be appropriate for all family members. Practical advice and written information should be made available about what to do after death and specialist bereavement support should be made available for those families who need it.

The National Care of the Dying Audit for Hospitals, England (2014) recommends that all hospitals should undertake local audit of care of the dying, including the assessment of the views of bereaved relatives, at least annually<sup>(24)</sup>.

#### Audit findings:

The verification of death needs to be done by a trained professional. Verification of death in the community is often delayed due to the availability of the out of hours GP service. This has a particular impact on certain groups where there is a cultural need for a rapid burial. One or two of the community nurses have undertaken training in order to be able to verify death but there are no policies in place at the moment to support this. Courses for nurses to be able to verify death are available via both Bluebell Wood and Rainbows children's hospices.

Support immediately after the death of a child at home is available via the community nurses, who attend to support in person in the home. All the community nursing teams support the family for several weeks after the death of a child in the community and then signpost to other bereavement support services depending on the needs of the family. Where there is no local child bereavement support service e.g. Northampton north, the community nurses will support the families for longer, often 12 months. The availability of more highly specialised child bereavement counselling services is variable and these are charity funded.

When a child dies in hospital the ward or special unit nurses support the family to have time and privacy with their child for several hours. Then the child's body will usually be transferred to the hospital mortuary. Derby Children's Hospital has a special cold bedroom, and there are two special bedrooms at Rainbows hospice which can be used by families even if the child did not die in the hospice.

Most local hospitals have a child bereavement team who can pick up the family rapidly for ongoing support and who may also have been involved in pre-bereavement work with the family to support choices, practicalities and preparations for the death. This pre bereavement work is hugely important to ensure everything goes as smoothly as possible and to reduce the family's regrets and 'if onlys' at a later stage. Some bereavement teams also support families whose child has died in the neonatal period and also have a bereavement midwife to support parents whose child has died before birth. The local child bereavement teams also provide practical and emotional support to the doctors and nurses managing the child's death including help with complex legal issues and supporting team debriefings and reflections. Written materials with practical advice regarding what to do after your child has died are widely used and available.

**Table 7. Child Bereavement Services**

Area	Specific child bereavement support service	Bereavement nurse for neonatal unit	Bereavement midwife	Specialist bereavement counselling service
Chesterfield	No	No	No	Yes
Derby	No	Family care team	Yes	Laura Centre
Leicestershire	No	Yes	Yes	Laura Centre
Northampton - North	No	No	No	No
Northampton - South	Yes	Yes	Yes	Laura Centre
Nottingham	Yes	Yes	Yes	No
Sherwood Forest	No	Family care team	No	No
Lincolnshire	Yes	Link nurse	Yes	??
Rainbows Hospice	Yes	Yes	??	Yes

Across the East Midlands all child deaths are reported to the coroner prior to there being permission to issue the death certificate. Electronic referral systems are in place and the service works well.

Some families will need more specialist **bereavement counselling services**:

These are mainly charity funded and are not universally easy to access.

- Rainbows bereavement counsellor
- Laura Centre in Leicester with subsidiaries in Derby and Northampton

Zephyr's Project – is a proposal for a bereavement centre in Nottingham through charity funding.

**Recommendations:**

- Explore the possibility of children's community nurses being trained and having policies in place to allow them to verify the death of a child in the community.
- All locality child bereavement services to be able to respond rapidly to the death of a baby in utero, neonate, child of any age, including sudden unexpected death: 24 hours per day, 7 days per week.
- Specialist child bereavement counselling services in all areas.
- All teams should have formal systems in place to collect feedback from bereaved parents and carers, at least annually, and to be able to use that feedback to improve the quality of the service.

**3.4 Transition**

**Quality standards:**

Transition to adult services should be planned jointly by children's and adult services and the transition journey should be started at an age and developmentally appropriate time. There should be a lead for transition in each of the provider organisations.

**Audit findings:**

All trusts apart from Sherwood Forest Hospitals have an identified paediatric lead for transition to adult services but rarely is there a corresponding lead for transition in adult services.

East Midlands Maternity and Children's Strategic Clinical Network Virtual Transition Group have developed guidelines for transition from children's to adult services:

<http://www.emsenatescn.nhs.uk/media/1588/final-em-best-practice-trans-d10-1-12-14.pdf>

There are clear pathways and joint clinics for transition to adult services for children with certain specific conditions including:

- cystic fibrosis
- muscular dystrophy
- cancer

There are some specific examples of good practice, including transition social workers and special school nurse for transition in Nottingham.

For many young people with complex disability and high health needs, adult services remain patchy and often fragmented. However it is expected that the education, health and care plan process should support improvement in the availability and coordination of services for some young people in further education.

#### **Recommendations:**

- There needs to be an identified transitions lead for Sherwood Forest Hospitals.
- All trusts should adopt the East Midlands best practice guidelines for transition from children's to adult services.
- All trusts should adopt the TFSL recommendations in Stepping Up<sup>(25)</sup>.
- Clinical commissioning groups should follow the recommendations in the TFSL transition guide<sup>(26)</sup>.

### **3.5 Education, training and competency monitoring**

#### **Quality standards:**

All staff caring for children and young people and their families with palliative care needs should be trained and have the appropriate skills and competence to meet the specific care needs of this client group. This includes medical, nursing, play, therapy, pharmacy and psychiatry staff.

There is increasing recognition nationally that education of all healthcare professionals regarding end of life care should be given a higher priority. The National Care Of the Dying Audit for Hospitals, England 2014<sup>(24)</sup> recommends that:

- Education and training in care of the dying should be mandatory for all staff caring for dying patients. This should include communication skills training and skills for supporting families.
- Education and training for care of the dying should be made a priority by Health Education England.

Several studies suggest that training in end of life care is more effective when it is practically reinforced<sup>(27)</sup>.

#### **Audit findings:**

- The Royal College of Nursing paediatric palliative care competency framework is used by the community nursing teams as a guide, but formal competency monitoring is rarely undertaken.
- All community nursing teams undertake regular individual appraisals and peer review. All teams arrange *ad hoc* workshops and study days.
- Training for paediatricians is part of the Royal College of Paediatrics and Child Health curriculum, however ongoing post graduate training is lacking.
- A level 3 degree module of children's palliative care is delivered by Nottingham University and some places each year are funded by Health Education East Midlands (HEEM). This funding is solely for the course fees for registered nurses or allied health professionals and does not provide funding to backfill posts. Other professionals working with children with life limiting conditions access the course with self or alternative funding. The course can also be studied at Master's level but this is not currently commissioned by HEEM.
- Advanced communication skills courses have been accessed by some professionals across the East Midlands, but funding for these courses has been *ad hoc*.

Several children's community nurses reported the need for more advanced level, scenario and practice based learning opportunities. In response to this Rainbows are proposing, from early 2016, to provide case based training sessions on two half days, twice per year, focusing on:

- communication and holistic emotional support
- end of life planning and symptom control

The training will be provided to community children's nurses initially but may be extended to other members of the community palliative care teams such as specialist family support workers.

### **Recommendations:**

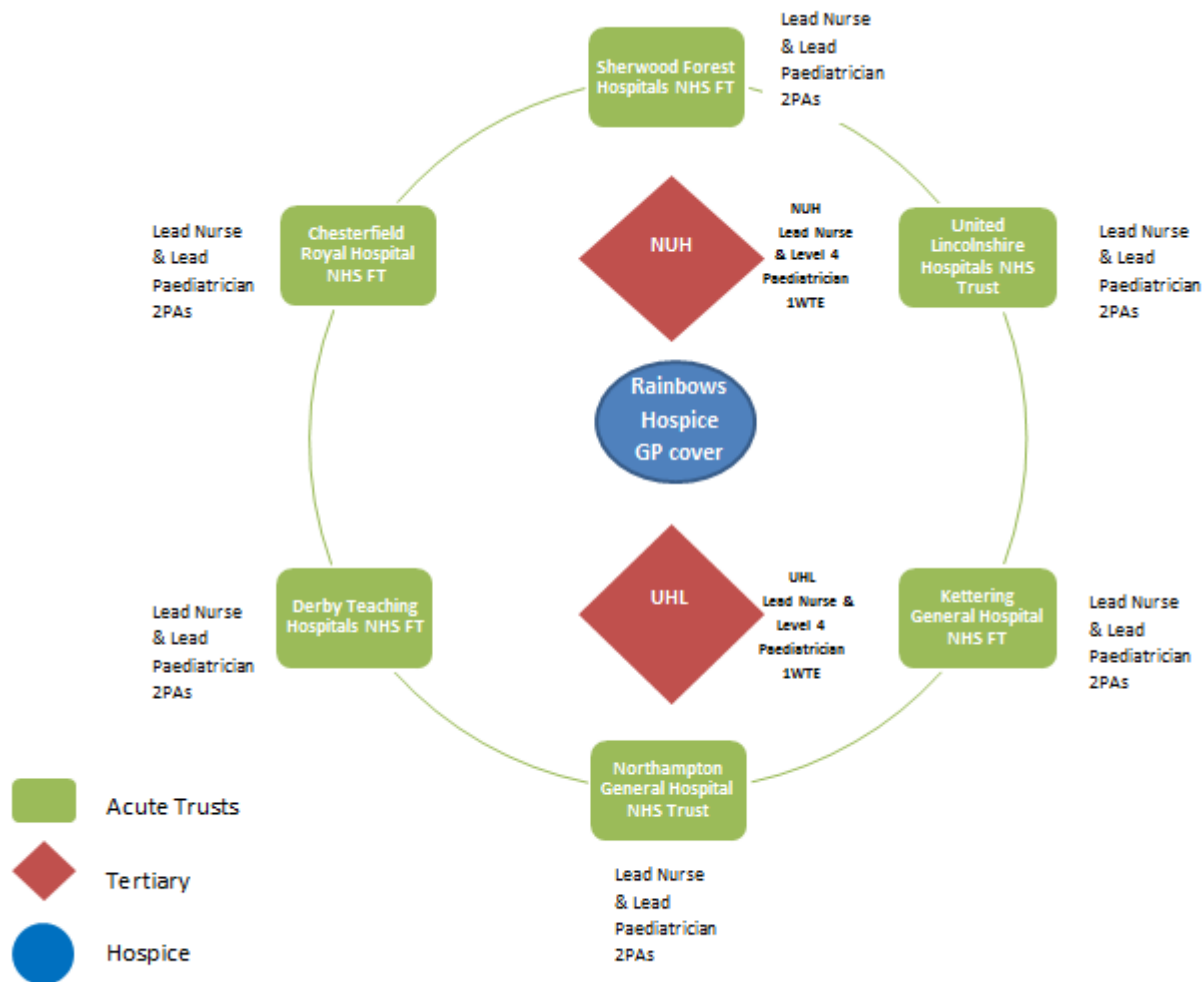
- There needs to be an education and training subgroup of the EMCYPPCN to take forward the education and training needs of the workforce on a regional level. This could be supported by the paediatrician with sessions for regional palliative care once this is commissioned.
- It is also recommended that HEEM commission:
  - a children's palliative care degree module at Master's level with opportunities for practice based learning.
  - an advanced communication skills course with 12 places per year for nurses and allied health professionals. This would fund 2 places for each local team per year. This course is also needed for paediatricians who could access it with study leave funding via their trusts.
- The e-ELCA programme, commissioned by the Department of Health and delivered by e-learning for Healthcare (e-LfH) in partnership with the Association for Palliative Medicine of Great Britain and Ireland aims to enhance the training and education of health and social care staff involved in delivering end of life care for adults, however, some of the interactive modules explore principles which are highly relevant to children's end of life care. Staff caring for children with palliative care needs could be given protected time to be able to access some of these modules <sup>(28)</sup>.

## **3.6 Conclusions**

There are many examples of good practice in place, for example the use across the region of the East Midlands Emergency Healthcare / Personal Resuscitation Plan to document resuscitation decisions for children and young people allows this documentation to be recognised by different organisations including the East Midlands Ambulance Service. All but one area of the region has a community children's nursing team. Some teams are specifically commissioned to provide 24 hr end of life care. Other teams are small but every effort is made to prioritise children needing end of life care and provide them with 24 hour support. When the community nursing teams are contacted they support children, young people and families to make choices about their care including place of death and will in-reach to support the discharge from hospital and the setting up of the symptom management plans. All the teams have established systems to ensure they have pharmacy and medical support. However the need for more practice- based, 'hands on' training was expressed and also the availability of advice from paediatricians with expertise in palliative care. The availability of bereavement support was variable, but generally the community nurses continue to support bereaved families for many months after the death of a child. Some services are heavily reliant on the expertise, experience, dedication and good will of one or two individuals. Such services are not sustainable in the long term.

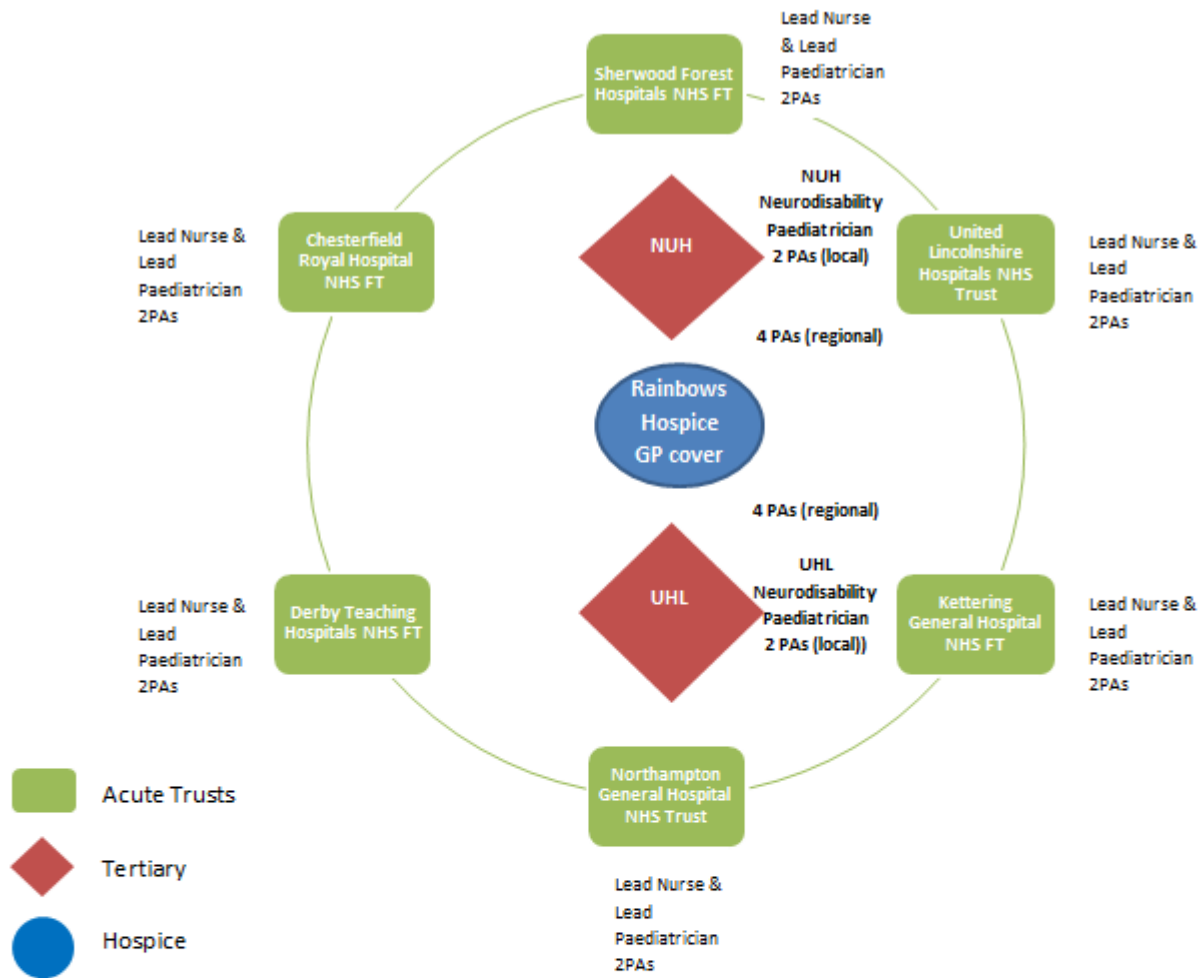
## 4. What Should the Future Service Look Like?

Figure 9. Diagram to show the ideal model of care



The above will work together with the children's community nursing services who will cover the entire population and be specifically commissioned to provide 24/7 end of life care in the community, which can be activated at any time.

Figure 10. Interim model of care



Provides 8 PAs for specialist palliative care paediatrician service at regional level

	NUH	UHL
Teaching, training audit and research	1PA	1PA
Ward rounds intensive care units PICU & NICU / joint clinics oncology	1PA	1PA
Complex Cases and Joint clinics with locality lead paediatricians	1PA	1PA
Clinical admin. / Professional development	1PA	1PA

NUH - Nottingham University Hospitals NHS Trust

UHL - University Hospitals of Leicester



## 4.1 Cost effectiveness of paediatric palliative care services

There have been several recent studies exploring the costs of end of life care in both children and adults which show that costs are considerably lower when care is out of hospital, even allowing for the commissioning costs of home-based care<sup>(29, 30)</sup>.

The government commissioned funding review<sup>(31)</sup> found that hospital admissions in the last year of life for children who need paediatric palliative care cost an estimated £18.2m. This far outweighs the cost of providing paediatric palliative care outside hospital.

The cost for a hospital admission for a child with a long term condition with acute respiratory illness is £2,400 for the first 10 days. The cost for paediatric intensive care is £2,800 per day per child<sup>(6)</sup>.

Bereavement services for parents and siblings before and following the death of a child can help to reduce the need for other services and interventions later in their lives.

## 4.2 Outcome measures

Currently there are no established formal outcome measures for children's palliative care.

The Children and Young People's Health Outcomes Forum Long-Term Conditions, Disability and Palliative Care Sub-group<sup>(32)</sup> recommend the following measures:

1. Getting a high quality multidisciplinary assessment that reflects all the child's or young person's needs, in addition to those of their family.
2. Getting a quality package of care (including a healthcare plan for emergency situations or an end of life plan where appropriate), fully integrated health, education and social care with access to key working support, information to enable the child or young person and family to manage the condition and ensure timely provision of equipment to support maximum participation.
3. Ensuring review of the care plan at key points of transition particularly transition to adult life and services.
4. Ensuring that the outcome indicators promote a whole family approach, because the health and well-being of family and carers directly impacts on children and young people and their resilience.

NHS England is currently funding a research project entitled Patient-Centred Outcome Measures (PCOM) for Children and Young People receiving Palliative Care: Identifying Common Priorities and Retaining Individual Flexibility<sup>(33)</sup>. This is based on the use of a web based tool – MyQuality which is available at [www.my-quality.net](http://www.my-quality.net)

There is also work underway to develop a children's version of the Palliative Care Outcome Scale<sup>(34)</sup>.

The National Institute for Health and Care Excellence (NICE) is developing a clinical practice guideline for end of life care for infants, children and young people. The report is expected to be published in December 2016 and will lead to quality standards and quality measures.

Commissioning a comprehensive care pathway for children and young people with life-limiting and life-threatening conditions can contribute to improvement in the following indicators in the Clinical Commissioning Group Outcome Indicator Set CCG OIS:

C2.1 Health related quality of life for people with long term conditions (NHS OF 2).

C2.2 People feeling supported to manage their condition (NHS OF 2.1).

C3.4 Emergency admissions for children with lower respiratory tract infections (NHS OF 3.2).

Domain four:

Improving the experience of care for people at the end of their lives.

Improving children and young people's experience of healthcare.

Improving people's experience of integrated care.

## 5. Actions for clinical commissioning groups

As recommended in the National End of Life Care Programme - Commissioning tool kit (35) and the Together for Short Lives - Commissioning guidance 2015 (36)

### 5.1 Build partnerships

Clinical commissioning groups should commission paediatric palliative care services in partnership with local authorities to ensure an integrated service.

### 5.2 Analyse and plan

- Get to know your local area's needs.
- Assess services and gaps.
- Agree quality outcome measures and incorporate into service specifications and contracts.
- Conduct user/carer consultations.
- Include children with life-limiting and life-threatening conditions in local joint strategic needs assessments and joint health and well-being strategies.
- Local groups of clinical commissioning groups should work together to assess demand and plan services effectively for these children who are relatively small in number but very costly for NHS resources.

### 5.3 Design pathways

Children's palliative care is very different from adult palliative care. Most children with life limiting or life threatening conditions will have severe disability and they may live for many years, so the paediatric palliative care pathway needs to be integrated with local pathways for disabled children and children's continuing care.

- Build on existing provision.
- Consider user views.
- Consider how effectively services meet the needs of hard to reach groups.
- Consider mechanisms for information sharing.
- Ensure robust processes for hospital discharge and out of hours care.

### 5.4 Specify and procure

- Commission a comprehensive local paediatric palliative care service including community children's nursing teams who can provide 24/7 end of life care, promptly, at any time.
- Specify the local paediatric medical support for the service, including identified paediatrician programmed activities for children's palliative care.

### 5.5 Deliver and improve

Clinical commissioning groups should support paediatric palliative care services in collecting and analysing data on performance and outcomes, so that ongoing service evaluation can lead to improvements and innovations. Data collection should include numbers of children with life limiting and life threatening conditions locally, and numbers of children dying from LLC and LTC and where they died

Feedback from families should be collected in a structured way and used to improve services

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## 8. Appendices

### Appendix 1 National policies and drivers for funding in paediatric palliative care

**Pre 2003:** Ad hoc development of services for children and young people with life-limiting and life-threatening conditions with pockets of excellent practice but insufficient sharing or generalisation.



**2003:** Funding boost to children's hospices and community children's nursing teams from the Big Lottery Fund



**2006:** £27 million over three years to further support children's hospices



**2007:** Independent review of paediatric palliative care commissioned by Secretary of State for Health, led by Sir Alan Craft and Sue Killen  
[http://webarchive.nationalarchives.gov.uk/20080814090217/dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_074459](http://webarchive.nationalarchives.gov.uk/20080814090217/dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_074459)  
Key messages: the need for **joint commissioning across health and social care** of high quality paediatric palliative care services based on assessed population needs (i.e. **accurate data collection**)



- 2007-2009:** Further reports echoing the same messages:
- Aiming High for Disabled Children  
<http://webarchive.nationalarchives.gov.uk/20130401151715/http://www.education.gov.uk/publications/eOrderingDownload/PU213.pdf>
  - Moving on Well [http://www.bacdis.org.uk/policy/documents/transition\\_moving-on-well.pdf](http://www.bacdis.org.uk/policy/documents/transition_moving-on-well.pdf)
  - Better Care, Better Lives <http://eprints.uwe.ac.uk/5178/1/Download.pdf>





**2010:** £30 million released by Department of Health (England) for projects and resources in paediatric palliative care (see [www.30millionstars.org.uk](http://www.30millionstars.org.uk) )  
Children's hospice and hospice-at-home grant initiated, continues to provide £10 million of Department of Health funding annually to 40 children's hospices in England.



**2011: Independent Palliative Care Funding Review** established under Sir Tom Hughes-Hallet, whose report recommended **robust data collection** and an **NHS per-patient tariff** for palliative care for children and adults to create a more transparent funding mechanism, encouraging **commissioning of integrated health and social care packages in the community**. See [www.gov.uk/government/publications/independent-palliative-care-funding-review](http://www.gov.uk/government/publications/independent-palliative-care-funding-review)



**2013: NHS England – Paediatric Palliative Care Service Specification.**  
The specification describes a 'hub and spoke' model with core paediatric palliative care services delivered by locality teams within a managed clinical network. With each network having a highly specialist palliative care team for clinical, educational and strategic support, led by a paediatric palliative care consultant with competency level 4.  
<http://www.england.nhs.uk/wp-content/uploads/2013/06/e03-paedi-med-pall.pdf>



**2015: Palliative care currency.**  
The currency is a first attempt to group specialist palliative care into packages of care that are similar in terms of resource need and clinical input. The currency is not mandatory and will be further tested and refined during 2015/16. The aim is that it will provide a meaningful tool to support service planning and commissioning and may lead to increased funding for palliative care services outside the hospital (*table 1*)  
<http://www.england.nhs.uk/wp-content/uploads/2015/03/dev-new-apprch-pallitv-care-fund.pdf>



**2015: End of life care for infants, children and young people – clinical practice guideline** is under development by National Institute for Health and Care Excellence (NICE)  
Report expected Dec 2016 and will lead to NICE Quality Standards for children's end of life care.

## Appendix 2 Extracts from NHS England – Paediatric Palliative Care Service Specification

This service specification will provide a consultant-led multi-professional specialist palliative care team, providing a clinical leadership role in planning, delivery and evaluation of children's palliative care services across a managed clinical network.

It will be led by a medical consultant working at Paediatric Palliative Care Competency Level 4.

It will provide both inpatient and outpatient care for those with life-limiting and life-threatening conditions and will provide the support of the multidisciplinary team.

Children's palliative care networks are defined by Together for Short Lives as "linked groups of health professionals and organisations from primary, secondary and tertiary care, and social services and other services working together in a coordinated manner with clear governance and accountability arrangements".

This specification will include the following:

- Care within a specialist paediatric unit (both in-patient and out-patient)
- Expert advice from a PPC specialist to other paediatric specialists within a referral centre - e.g. paediatric intensive care, oncology, endocrinology, cardiology, urology
- Outreach clinics with the specialist and the general paediatrician in the local hospitals, hospices and community settings, including schools
- Expert advice from a PPC specialist to the local hospital's general paediatrician caring for the child or, less commonly, to the GP, by letter, telephone, email, face to face or videoconferencing
- Expert advice from non-medical multi-disciplinary team members to other healthcare providers e.g. specialist nurses, dieticians, psychologists, pharmacists etc. by letter, telephone, email, videoconferencing or face to face
- Visits from members of the multi-disciplinary team to the patients home and school to provide assessment, training and support to the child, family and other carers
- Transition pathways of care to adult services
- Multi-disciplinary meetings for paediatric palliative care, including specialist paediatric palliative care interventions, usually involve some or all of the following components:
  - Assessment of need (e.g. pain assessment)
  - Planning of care (e.g. planning for management of increased pain anticipated in association with disease progression)
  - Delivery of care (e.g. changing the contents of a syringe driver of medication infused at home for end of life care). Interventions are likely to fall into one or more of the following categories:
    - > communication (breaking bad news/ dealing with collusion)
    - > advance care planning
    - > emergency healthcare planning
    - > clinical ethics
    - > co-ordination of care/ key working
    - > discharge planning, including rapid discharge to facilitate end of life care in the setting of choice for child and family
    - > education (of patient/ family)
    - > social support (for the patient, or family, including siblings)
    - > psychological support (for the patient, or family, including siblings)
    - > non-drug symptom management techniques such as guided imagery, massage
    - > pre-bereavement and bereavement support (for child and family, including siblings)
    - > pain management
    - > symptom management, other than pain
    - > short break care away from home
    - > short break care at home, school or other community setting
    - > end of life care (care in the last hours and days of life) including provision of 24 hours a day, 7 days a week, on call service
    - > transition to adult services

The service will provide the full range of specialist paediatric palliative care interventions including complex symptom management, and acute end of life care for both oncological and non-oncological diseases. Examples include management of complex neuropathic pain, and management of other refractory symptoms, and will involve specialist pharmacological knowledge, such as the use of alternative opioids (e.g. methadone), and a wide range of off label and unlicensed use of medicines, conducted within an appropriate framework of clinical governance to ensure safety.

The multi-professional service will also be responsive to new developments in the field such as the use of patient controlled analgesia and where appropriate will aim to support their implementation in a timely manner, in as much as they can be supported by local services.

It is anticipated that in the majority of cases specialist paediatric palliative care will be provided to children who are thought to be in the last few weeks (red), months or years (amber) of life as identified by the spectrum of children's palliative care needs.

The service is commissioned to provide care for children as close to home as possible with the local hospital, community services and children's hospice providing as much of the care as possible. This is achieved by creating clinical networks with each local service within the clinical network having at least one clinical lead taking responsibility for children with palliative care needs and the specialist PPC service providing support to the local lead where appropriate. This may include the provision of outreach clinics in the district hospital or children's hospice led by the PPC specialist. Each local service would be required to work within the network and comply with agreed standards with appropriately qualified doctors, nurses and allied health professionals. The place of care will depend on the clinical need and patient choice.

The PPC specialist will be supported by a care team led by a senior nurse (level 7/8).

The multi-disciplinary team essential to support the running of a PPC service will include:

- medical staff
- nurses (including those with special expertise in PPC e.g. symptom management)
- pharmacists
- social workers
- psychologists
- play specialists/youth workers

Services will be provided in partnership with local services, 24 hours a day, seven days a week, according to the identified need of the child and family.

Specialist palliative care telephone advice will be available to network providers 24 hours a day, 7 days a week.

Specialist palliative care telephone advice will be available to patients, parents and carers known to the service and will be available 24 hours a day, 7 days a week.

### **Population covered**

It is proposed that there should be at least one PPC specialist service per network, with a maximum of one specialist paediatric palliative care team for each population of 1-2 million people.

The geographical area covered, and the population served by each network, does vary and thus the model of service will be slightly different for each region. However, the aim is to develop networks of care, led by the lead specialist centres co-ordinating care with the secondary care, primary care and third sector providers. The commissioning level for a PPC service should be serving a population of between 1-2 million people. York Economics Consortium (Lowson et al 2007) recognises that the relatively small numbers of children and young people within a population of 250,000, and the specialist nature of the services, points to the advisability of planning these services for a larger population of at least 1 million, or even at a strategic health authority level (i.e. 4 million).

The configuration of specialist palliative care services must take into account location of relevant specialist services such as paediatric intensive care units (PICU) and cancer centres as well as patient flows.

Children, up to the day before their 19th birthday, with life-limiting/life-threatening conditions will have access to this service. However, young people will usually be transferred to adult services prior to their 18th birthday. Palliative care services, including specialist paediatric palliative care should be accessible to babies, children and young people with:

- critical illness on neonatal and paediatric intensive care units
- cancer
- severe congenital heart disease and cardiomyopathies
- muscular dystrophies and spinal muscular atrophy
- spastic quadriplegic cerebral palsy
- severe inborn errors of metabolism
- multiple congenital malformations
- significant chromosomal anomalies
- some children with cystic fibrosis
- some children who are technology-dependent
- some children with undiagnosed conditions which are clearly life-shortening. These children must be included even if they do not have a diagnostic label

### Appendix 3 Paediatric palliative care competency levels

Level	Description	General principles
Level 1	Doctor just completing a primary qualification.	Understand the basic principles of paediatric palliative care.
Level 2	Paediatric trainee after completing higher specialty core training or a GP/children's hospice doctor after a well-supported period of paediatric palliative care experience.	Apply basic principles of palliative medicine to the care of children specifically. Recognise reversible causes of symptoms in children, whether with a life-limiting condition or not.
Level 3	A paediatrician (consultant or staff or associate specialist (SAS) doctor) who has developed a special interest in PPM, an established children's hospice doctor or GP with Special Interest (GPWSI) in paediatric palliative care. Likely to have a relevant postgraduate qualification such as the Cardiff Diploma in Palliative Medicine (paediatrics).	Be able to manage most common symptoms safely and effectively. Be prepared to recognise need for specialist help and access it where necessary.
Level 4	A consultant paediatrician in PPM, or a small number of children's hospice medical leaders (mainly leaders in sub-specialty formation and development, and with roles beyond their local hospice), and who have a substantive role in children's palliative medicine.	Manage uncommon symptoms; understand principles in order to develop a logical approach even where there is no evidence basis. Considerable emphasis on leading and developing services within and beyond the local hospice, and on supporting and teaching other professionals involved with children with life-limiting conditions who are not trained in palliative medicine.

While the specific standards for each competency would, of course, depend on its nature, the general principles were used to define the different levels.

Association of Paediatric Palliative Medicine

## Appendix 4 Audit tool used in the East Midlands children’s palliative care audit

Quality standards for services providing palliative care for children and young people – adapted from the self-assessment tool developed in West Midlands Children’s Palliative Care Network (WMPCN).

<b>Organisation:</b>	
<b>Completed by:</b>	
<b>Head of Children’s Services:</b>	
<b>Service Manager:</b>	

Quality Standard Item	Providers’ Self-Assessment	Review Notes	Visit
<p><b>Personalised Care Planning</b>            Each child and young person and family should have the opportunity for discussion and agreement of their plan of care. This should be confirmed in a written Personal Care Record which is communicated to all services involved in their care and which is updated regularly and reviewed at least annually. The plan of care should cover:</p> <ol style="list-style-type: none"> <li>a. Agreed goals, including ‘parallel planning’ goals</li> <li>b. Therapeutic interventions (pharmacological and non-pharmacological)</li> <li>c. Equipment used</li> <li>d. Care provided by the child, young person and their family and any training needed</li> <li>e. Name of the person taking a ‘key working’ function and their contact details</li> <li>f. Names and contact details of professionals and services involved in their care</li> <li>g. Education and education plan covering, at least, nursery, school or college attended and arrangements for liaison with them</li> <li>h. Choices and options for short breaks</li> <li>i. Housing and any housing adaptations needed</li> <li>j. Religious, spiritual and cultural needs</li> <li>k. Transport arrangements and transport needs</li> <li>l. Early warning signs of problems and what to do if these occur, including ‘just in case’ medication (if appropriate)</li> <li>m. How to access advice and support, including out of hours.</li> <li>n. Planned review date and how to access a review more quickly, if necessary.</li> <li>o. Transition to adult services (if applicable)</li> </ol> <p>This QS should be met once for each child or young person (<b>not</b> once in each service).</p>			
<p><b>Advance Care Plan</b>            Each child or young person and their family should have an Advance Care Plan. The Advance Care Plan should be</p>			

Quality Standard Item	Providers' Self-Assessment	Review Notes	Visit
<p>communicated to all relevant services involved in the care of the child or young person and should include a review date. If an Advance Care Plan is not yet appropriate, this should be documented in the child or young person's medical record.</p>			
<p><b>Bereavement Support</b>            Families experiencing more complex grief should have access to a service providing ongoing, more specialist bereavement support including:</p> <ol style="list-style-type: none"> <li>a. Support for the child or young person</li> <li>b. Pre- and post- bereavement support for the family, including siblings</li> </ol> <p><i>Note: This QS is additional to the bereavement support provided by all staff working in paediatric palliative care.</i></p>			
<p><b>Involving Children, Young People and Families</b>            The service should have:</p> <ol style="list-style-type: none"> <li>a. Mechanisms for receiving feedback from children, young people and their families about the treatment and care they received.</li> <li>b. Mechanisms for involving children, young people and families in decisions about the organisation of the service.</li> <li>c. Examples of changes made as a result of feedback and involvement of children, young people and their families.</li> </ol> <p><i>Note: The arrangements for receiving feedback from children, young people and families may involve surveys, including the national patient survey, focus groups and/or other arrangements. They may involve Trust-wide arrangements so long as issues relating to the specific service can be identified.</i></p>			
<p><b>Staffing Levels</b>            The service should have sufficient staff with appropriate competences for the usual number of children and young people cared for by the service, their dependency, the complexity of their needs and, for children thought to be in the final days of life, for undertaking visits and, if necessary, providing care in the preferred place of death. Staffing should include:</p> <ol style="list-style-type: none"> <li>a. Medical staff (see note 1)</li> <li>b. Nursing staff, health care assistants and support workers (see note 4)</li> <li>c. Other staff providing support and care for children and young people needing palliative care who are part of the services' 'core team'.</li> </ol> <p>Cover for absences should be available so that the functions of the service can continue during times of annual leave, study leave and short-term sickness.            Community services should have sufficient staffing to care for at least two children in the final days of life <b>or</b> should have a contingency plan covering this eventuality and</p>			

Quality Standard Item	Providers' Self-Assessment	Review Notes	Visit
<p>which can also be used if staffing levels are reduced due to maternity leave or long-term sickness.</p> <p><i>Notes:</i></p> <p>1 All services should have access to an appropriate paediatrician at all times that the service is operational and some medical time allocated to work with the service.</p> <p>2 For children's hospices, as with each local area, at least one member of the medical team should have level 3 competences in Paediatric Palliative Medicine.</p> <p>3 Staffing may include volunteers with appropriate competences.</p> <p>4 RCN "Defining Staffing Levels for Children's and Young People's Services" gives advice on sufficiency of staffing. Many children with palliative care needs will require high dependency care and recommended staffing levels are: level 3 2:1; level 2 1:1; Level 1 1:2. Ward nursing establishments should be based on the level of clinical care each child / young person needs as determined by a patient dependency tool. The following provides an indicative baseline ration of registered nurses to children / young people taking into account the distinct care requirements linked to age and development: a) under 2 years 1:3; b) for other ages: during the day 1:4 and during the night 1:5.</p> <p>5 Cover for absences may be achieved through agreed arrangements with another service.</p> <p>6 This QS can be met if the service has only medical and nursing staff as part of</p>			
<p><b>Nominated Lead for Transition</b></p> <p>The service should have a nominated lead for transition to adult care of young people with complex and palliative care needs.</p> <p><i>Note: The nominated lead for transition may be the lead paediatrician or lead nurse or may be different.</i></p>			
<p><b>Care around the time of death</b></p> <p>Guidelines on care around the time of death should be in use covering, at least, arrangements for:</p> <ol style="list-style-type: none"> <li>a. Rapid discharge, including: <ol style="list-style-type: none"> <li>i. Agreement with receiving services that care can be provided by them</li> <li>ii. Communication with the general practitioner</li> <li>iii. Communication with all services involved in the child or young person's care</li> </ol> </li> <li>b. If necessary, review of the choice of preferred place of death and transfer to an alternative setting</li> <li>c. Clinical review and assessment, including liaison with the general practitioner and 'local area' lead palliative care paediatrician</li> <li>d. Support for the family, including in the period immediately after the death</li> <li>e. Supply and disposal of medication and oxygen</li> <li>f. Supply and removal of equipment</li> </ol>			



Quality Standard Item	Providers' Self-Assessment	Review Notes	Visit
<p>g. Verifying, certifying and registering the death  h. Care and, if applicable, transfer of the child's body  i. Ensuring compliance with the Child Death Review Process</p> <p>Guidelines should ensure appropriate recognition of families' spiritual and cultural needs.</p> <p><i>Notes:</i>  1 Use of the West Midlands Children and Young People's Palliative Care Toolkit guidelines on 'Rapid discharge for care at end of life' is sufficient for compliance with (a).  2 Services should be aware that 'continuing care assessments' should not be required for children and young people thought to be in the final days of life.</p>			
<p><b>Transition to Adult Care</b></p> <p>Guidelines on transition to adult care should be in use, covering:</p> <ul style="list-style-type: none"> <li>a. Age guidelines for timing of transition</li> <li>b. Involvement of the young person and their family in the decision about transition</li> <li>c. Multi-disciplinary planning of the transition with primary health care, social care, education service and adult services</li> <li>d. Joint meetings with the young person, their family and children's and adult services prior to transition</li> <li>e. Responsibility for key working functions during the transition period</li> <li>f. A preparation period and education programme relating to transition to adult care</li> <li>g. Arrangements for monitoring during the time immediately after transition to adult care</li> </ul> <p><i>Note: The ACT Transition Pathway and Service self-assessment tool provide resources for the development and assessment of local guidelines.</i></p>			
<p><b>Competence Framework and Training Plan</b></p> <p>All staff should be working towards and, when achieved, should be maintaining competences appropriate to their role in:</p> <ul style="list-style-type: none"> <li>a. Philosophy of palliative care</li> <li>b. Symptom control , including: <ul style="list-style-type: none"> <li>i. Pain evaluation</li> <li>ii. Pain management</li> <li>iii. Nausea, vomiting and reflux</li> <li>iv. Constipation, anorexia, cachexia and hiccough</li> <li>v. Mouth care, feeding and hydration</li> <li>vi. Dyspnoea</li> <li>vii. Seizures and other neurological and neuromuscular problems</li> <li>viii. Psychological symptoms</li> <li>ix. Skin symptoms</li> </ul> </li> <li>c. Emergencies</li> </ul>			

Quality Standard Item	Providers' Self-Assessment	Review Notes	Visit
<p>d. Ethics and Law  e. Care immediately around the time of death  f. Practicalities around death  g. Advanced communication skills  h. Use of palliative care equipment  i. Psychosocial support  j. Play support  k. Working with children with emotional and behavioural difficulties  l. Bereavement support</p> <p>A competence framework should show the competences expected for different roles within the service and a training plan should cover achievement and maintenance of these competences.</p> <p><i>Notes:</i>  1 This QS applies to all staff identified in QS except doctors in training where expected competences are laid down by the relevant Royal College. The Coventry and Warwickshire Children and Young Peoples Interactive Competency Framework may be helpful in achieving this QS and can be found at <a href="http://www.covandwarkschildcomps.org.uk">www.covandwarkschildcomps.org.uk</a> . Further guidance on competences needed is available from the Royal College of Nursing or Skills for Health <a href="http://www.skillsforhealth.org.uk">www.skillsforhealth.org.uk</a>  2 This QS is additional to the competences of everyone working with children, including: Safeguarding of children and young people; Life support; Information</p>			

## Appendix 5 Self-assessment and evaluation tool for children and young people with palliative care needs

A Framework for the Delivery of Palliative Care for Children and Young People in Scotland  
<http://www.gov.scot/Publications/2012/11/8118/4>

Key Objectives	Assessment and Evaluation Questions	Does Your Health Board Have This in Place? YES/NO	Available Tools, Pathways, Policies and Training
<b>Lead doctor and nurse for children and young persons palliative care</b>  Every Health Board should ensure that there is an identified lead doctor and nurse within the children's services for palliative care	Have you identified a lead doctor and lead nurse within your children's services for palliative care for children and young people		National Delivery Plan for Children and Young People's Specialist Services in Scotland (2008).  Building on progress reference
<b>Identification of all children and young people with palliative care needs</b>  Every Health Board should ensure that all children and young people with palliative care needs in their area are identified	Are all the children and young people in your health board area with palliative care needs identified?		Hain's Dictionary  Surprise Question  Act Categories of palliative care  Act Service Self assessment tool  Electronic Palliative Care Summary (EPCS)
<b>Breaking bad news</b>  Every family should receive the news of their child's diagnosis in a face-to-face discussion in privacy and should be treated with respect, honesty and sensitivity	Is diagnosis shared with parents in a face-to-face discussion (using an interpreter if necessary)?  Are private settings available for breaking bad news?  Are parents encouraged to have another relative or friend present to provide support?  Is appropriate written material provided for parents and children?		Training for staff on communication and breaking bad news  Communicating with Children and Young People 0-18 years (GMC, 2007)  Psychosocial Interventions -Education Resource Children and Young people. <a href="http://www.gmc-uk.org/Paediatric_Palliative_Medicine_FINAL.pdf_30456043.pdf">www.gmc-uk.org/Paediatric_Palliative_Medicine_FINAL.pdf_30456043.pdf</a>

<p><b>Assessment of care needs and multi-agency care plan</b></p> <p>Every child and family should receive a multi-agency assessment of their palliative care needs and have a multi-agency care plan agreed with them that identifies a key worker for the family and provides co-ordinated care and support to meet these needs</p>	<p>Is a lead paediatric consultant identified for each child or young person?</p> <p>Is a lead professional/key worker identified for every child or young person?</p> <p>Does each child or young person have a multi-agency care plan agreed?</p> <p>Is every child, young person and their family given choices about the care they receive?</p>	<p>Building on progress <a href="http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell/buildingonsuccess">http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell/buildingonsuccess</a></p> <p>Children's Hospice association of Scotland - Plan 2011-2016 Care, Support, Connections (2011) <a href="http://www.chas.org.uk">www.chas.org.uk</a></p> <p>Training and education for all staff involved in C&amp;YP palliative care within hospital and community setting</p> <p>NHS Lothian Anticipatory Care Plan for children and young people (<a href="#">Appendix 3</a>)</p> <p>Girfec, Implementation Plan (Scottish Executive, 2006)</p> <p>A care pathway for children and young people with life-threatening and life-limiting conditions related to severe acquired brain injury. <a href="http://www.thechildrenstrust.org.uk/page.asp?section=1703&amp;sectionTitle=Palliative+care+pathway+for+acquired+brain+injury">http://www.thechildrenstrust.org.uk/page.asp?section=1703&amp;sectionTitle=Palliative+care+pathway+for+acquired+brain+injury</a></p> <p>Seen and Not Heard (Long term conditions alliance Scotland, 2010)</p> <p>Square table Evaluation Report - together for short lives. <a href="http://www.act.org.uk/core/core_picker/download.asp?id=972">http://www.act.org.uk/core/core_picker/download.asp?id=972</a></p>
<p><b>Planning discharge</b></p> <p>Every child and family diagnosed with palliative care needs in the hospital setting should have an agreed discharge plan. This should include tertiary and secondary hospital services, community services and voluntary services as required</p>	<p>Is the GP and community services included in the planning before the child is discharged?</p> <p>Are families and carers trained prior to discharge?</p> <p>Are essential resources available?</p> <p>Have arrangements been made for regular review of the anticipatory care plan?</p>	<p>Care Pathway for Children and Young People with Palliative Care Needs in Hospital (2010) (<a href="#">appendix 5</a>)</p> <p>Discharge Pathway for Children with Exceptional Health Care Needs MCN for Children with Exception Health Care Needs: <a href="http://www.cen.scot.nhs.uk/">http://www.cen.scot.nhs.uk/</a></p> <p>Anticipatory Care Plans (Lothian HB ACP for children <a href="#">appendix 6</a>)</p>
<p><b>Recognition and planning for end of life care</b></p> <p>Every child and family should be supported to decide on an end of life plan including choice of place of care and place of death once the end of life stage is recognised</p>	<p>Are families supported to make realistic choices about place of care and death?</p> <p>Do families have access to 24-hour symptom control?</p> <p>Are families provided with a 24-hour contact number?</p> <p>Do all children and young people who are recognised to be in the end-of-life stage have an agreed resuscitation plan?</p>	<p>Care Pathway for Children and Young People with Palliative Care Needs in Hospital (2010) (<a href="#">appendix 5</a>)</p> <p>Just in Case Box (<a href="http://www.rcn.org.uk/_data/assets/pdf_file/0009/270873/4.7.2_Palliative_care_drug_boxes.pdf">http://www.rcn.org.uk/_data/assets/pdf_file/0009/270873/4.7.2_Palliative_care_drug_boxes.pdf</a>)</p> <p>Paediatric Resuscitation Policy for Scotland <a href="http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell/CYPADM/CYPADMPolicydocument">http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell/CYPADM/CYPADMPolicydocument</a></p> <p>Rainbows Children's Hospice: Basic Symptom Control in Paediatric Palliative Care - 8th Edition <a href="http://www.act.org.uk/page.asp?section=167&amp;sectionTitle=Basic+symptom+control+for+children%27s+palliative+care">http://www.act.org.uk/page.asp?section=167&amp;sectionTitle=Basic+symptom+control+for+children%27s+palliative+care</a></p> <p>ACT GP work book: <a href="http://www.act.org.uk/page.asp?section=411&amp;sectionTitle=Children%27s+palliative+care+handbook+for+GPs">http://www.act.org.uk/page.asp?section=411&amp;sectionTitle=Children%27s+palliative+care+handbook+for+GPs</a></p> <p>The Association for Paediatric Palliative Medicine (APPM) was formed in November 2009 following a merger of the Children's Hospice UK doctors group and the British Society for Paediatric Palliative Medicine (BSPPM). <a href="http://www.act.org.uk/landing.asp?section=385&amp;search=formulary">http://www.act.org.uk/landing.asp?section=385&amp;search=formulary</a></p> <p>Liverpool care pathway (young adults)</p> <p>CHAS end-of-life care plan.</p>

<p><b>Care after death</b></p> <p>Following the death of a child or young person every family should be allowed time and privacy with their child. Bereavement support should be offered for as long as the family requires this and should be appropriate for all family members</p>	<p>Are families given time and privacy with their child after death?</p> <p>Is practical advice and written information available about what to do after death?</p> <p>Is bereavement support available for parents and siblings for as long as required?</p>	<p>Shaping Bereavement Care (Scottish Government, 2010).</p> <p>Training and education for all relevant staff in bereavement.</p> <p>What to do after death booklet</p> <p>Children's Hospice Association Scotland (CHAS) <a href="http://www.chas.org.uk/">http://www.chas.org.uk/</a></p> <p>Winstons wish <a href="http://www.winstonswish.org.uk">www.winstonswish.org.uk</a></p> <p>Child bereavement trust <a href="http://www.childbereavement.org.uk">www.childbereavement.org.uk</a></p>
<p><b>Transition</b></p> <p>Health Boards should develop local pathways for transition of young people to appropriate adult services</p>	<p>Is transition to adult services planned jointly by children's and adult services?</p> <p>Is the transition journey started at an age and developmentally appropriate time?</p>	<p>Act Transition Pathway</p> <p>Think Transition Document RCPE 2008</p>
<p><b>Education and training</b></p> <p>All staff, caring for children and young people and their families with palliative care needs, should be trained and have the appropriate skills and competence to meet the specific care needs of this client group</p>	<p>Do all paediatric staff have the skills and competencies to deliver safe, effective, efficient and timely palliative care for children and young people in their Health Board area?</p> <ul style="list-style-type: none"> <li>▫ Medical</li> <li>▫ Nursing</li> <li>▫ Play</li> <li>▫ AHPs</li> <li>▫ Pharmacists</li> <li>▫ Psychologists</li> </ul> <p>Do all primary care staff have the skills and competencies to deliver safe, effective, and timely palliative care for children and young people in their Health Board area.</p>	<p>Training in communication and palliative care</p> <p>In house training NES training; HEI programmes</p> <p>Principles of Nursing Practice (Royal College of Nursing, 2010)</p> <p>Royal College of Nursing (2002) A framework for nurses working in specialist palliative care: Competencies project, London: RCN. Publication code 001 958.</p> <p>Royal College of Nursing (2002) Nursing education: a statement of principles, London: RCN. Publication code 001 495.</p> <p>Royal College of Nursing (2002) Nurse staffing in children's wards and departments - results of a Delphi study (unpublished report by RCN Paediatric Nurse Managers Forum).</p> <p>Royal College of Nursing (2003)</p> <p>Children and young people's services: Pre-registration nursing education, London: RCN. Publication code 001 996.</p> <p>Royal College of Nursing (2003) Preparing nurses to care for children and young people. Summary position statement by the RCN Children and Young People Field of Practice, London: RCN. Publication code 001 997.</p> <p>Royal College of Nursing (2003) Children and young people's nursing: a philosophy of care: Guidance for nursing staff, London: RCN. Publication code 002 012.</p> <p>Royal College of Nursing (2003) Children's community nursing - Promoting effective team working for children and their families, London: RCN. Publication code 000 878.</p> <p>Royal College of Nursing (2003) Caring for young people: guidance for nursing staff, London: RCN. Publication code 001 824.</p> <p>Psychosocial Interventions -Education Resource Children and Young people. <a href="http://www.knowledge.scot.nhs.uk">www.knowledge.scot.nhs.uk</a></p> <p>West Midlands Children and Young peoples palliative Care Toolkit. <a href="http://www.act.org.uk/page.asp?section=417&amp;sectionTitle=West+Midlands+Children+and+Young+People%27s+Palliative+Care+Toolkit">http://www.act.org.uk/page.asp?section=417&amp;sectionTitle=West+Midlands+Children+and+Young+People%27s+Palliative+Care+Toolkit</a></p> <p>Association for Paediatric Palliative Medicine (APPM) <a href="http://www.palliativecareguidelines.scot.nhs.uk/documents/APPM_Master_Formulary_V1_1[1].pdf">www.palliativecareguidelines.scot.nhs.uk/documents/APPM_Master_Formulary_V1_1[1].pdf</a></p> <p>Royal College of Paediatrics and Child Health <a href="http://www.rcpch.ac.uk/">http://www.rcpch.ac.uk/</a></p>

## Appendix 6 Example of specialist family support service for children with life-limiting and life-threatening conditions



### **The Butterfly project - Nottingham City and South County**

The Butterfly Project is funded by local health commissioners.

The team consists of a team manager, two project workers, a volunteer co-ordinator and volunteers. We provide comprehensive support to children and young people with life limiting illnesses and their families from diagnosis to bereavement.

The Butterfly project provides sensitive, skilled practical and emotional support to children and young people with life limiting and life threatening conditions, their parents and siblings. This includes:

- Practical help and advice along the child's journey in partnership with a wide range of medical professionals.
- Individual work with the child/young person in respect to hopes, fears, dreams and wishes. Opportunities for them to participate in a variety of activities and have meaningful experiences.
- Emotional support so families can explore and express their feelings and make informed choices around their child's 'end of life care'.
- A post bereavement service of two years for bereft siblings and parents
- Sibling support groups and workshops, allowing young people to talk about and understand their feelings and to also have some fun
- Parent support groups both pre and post bereavement
- Family days

We support individuals in their family homes and within the community. We run support groups in Beeston and Bullwell. Family days and specific event days are held in various venues across the county. We will provide transport for some young people to groups or specific activities.

The team's core hours are 9am to 5pm, Monday to Friday.

Due to the varied work we undertake, we work flexibly and provide support in the evenings and weekends according to the young person's and the family's assessed needs and the outcomes required.

## Appendix 7 Contributors:

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Laura Few, Senior Nurse Manager, Northamptonshire Healthcare NHS Foundation Trust

Beverly Waithe, Children's Community Matron and Jackie Browne, Child Bereavement Team at Nottingham University Hospitals NHS Trust.

Deborah Flatman, Matron, Julia O'Dwyer, Acting Children's Community Matron, Sue Bennion, Head of Nursing and Midwifery and Dr Dougie Thomas, Consultant Paediatrician at United Lincolnshire Hospitals NHS Trust.

Nicky Brett and Laura Churm, Kite Team, and Julie Mott at Royal Derby Teaching Hospitals NHS Foundation Trust.

Sue Hancock, Children's Complex Needs and Palliative Care Specialist Nurse & Dr Helena Clements, Children's Clinical Director at Sherwood Forest Hospitals NHS Foundation Trust.

Carmel Stagles, Head of Nursing Children's Services, Dr Roby Mathew, Children's Clinical Director and Rosie Wilson at Chesterfield Royal Hospital NHS Foundation Trust.

Alison Cooke, Director of Care, plus Jo Simms and Jenny Taylor, and Dr Sat Jassal at Rainbows Children's Hospice, Loughborough.

Linda Connolly, Senior Nurse Manager at Nottinghamshire Healthcare NHS Foundation Trust.

