



The

# Big Study

for Life-limited Children  
and their Families

An overview



LOTTERY FUNDED

Together for Short Lives, October 2012

**The Big Study for Life-limited Children and their Families\* – How well are the palliative care needs of children with life-limiting conditions and their families met by services in the West Midlands?**

\*also known as The Big Study for Better Care for Children and Families

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Together for Short Lives is the leading UK charity for all children with life-threatening and life-limiting conditions and all those who support, love and care for them. When children are unlikely to reach adulthood, we aim to make a lifetime of difference for them and their families.

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The full research report is available at  
[www.togetherforshortlives.org.uk/thebigstudy](http://www.togetherforshortlives.org.uk/thebigstudy)

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# Foreword

It's a huge privilege to be able to present this overview of the Big Study for Life-limited Children and their Families (the Big Study).

The germ of the idea for the Big Study began at least five years ago at an ACT Board meeting where we were discussing how far children's palliative care had come since its early days and yet how little we really knew about whether children's palliative care services were meeting the needs of children and families. We wanted to know what was missing from the jigsaw and which needs were well met. I would like to give especial thanks to Dr Anne Hunt for working with the team at Together for Short Lives to develop the initial proposal and without whose vision the project would not have been possible. The idea for a major research study to be based in the West Midlands took hold and we approached a number of key researchers in the field as collaborators, developed the proposal, and were delighted that funding was awarded from the Big Lottery Fund to bring the germ of an idea to fruition. Since this time, ACT has merged with Children's Hospices UK to form Together for Short Lives.

The Big Study has been a complex study with many partners through its two year duration. Those involved in research will know that research with families of children with life-limiting and life-threatening conditions is difficult and that research ethics governance procedures make it difficult to access and work with families within NHS sites. Despite these complexities and thanks to the expertise of our research partners and the skills of our wonderful project manager, Julia Hodgson, the Big Study has delivered its findings and we were able to work with data from almost 1300 families across the West Midlands region. We really are indebted to those families who took part and to the many professionals and services who worked alongside us to provide such a rich seam of data.

There is so much rich data within this Study that it is difficult to do it justice within a few short words. While this document tells the outline story of the Big Study, I hope very much that you will also read the full research report (at [www.togetherforshortlives.org.uk/thebigstudy](http://www.togetherforshortlives.org.uk/thebigstudy)) which provides the full detail of all the findings from the five strands of research that made up the project as a whole.

It was encouraging to learn that some services such as children's hospices and community children's nursing teams (where they are well resourced) are highly praised. On the whole it seems that families feel that the medical and nursing needs of their children are relatively well met, but it is the provision of broader financial, social, emotional and short break support for families which is falling short, alongside the need for more responsive physiotherapy and occupational therapy. As with many other studies, the issue of poor communication and coordination between services was also highlighted. While it was found that the children's palliative care network provides a huge benefit in terms of professional collaboration and sharing of best practice, the network is not yet perceived by families to be delivering better joined up services.

The economic analysis of the data has shown that while the trend towards more home-based care is what most families want, it does place a huge caring and financial burden on families. The availability of short breaks and support for parent/carers and siblings must increase to meet the needs of families who are taking on complex caring roles.

The Big Study has raised many questions for the future and highlighted further research that is needed. Together for Short Lives will be using the findings from this research to inform its campaigning and other activity and plans to continue to work on developing future projects to answer some of the research questions that have been raised. Our commitment to working in partnership with children, young people and families remains as strong as ever, and we look forward to working with some of the families from the Big Study in our future work.



**Lizzie Chambers**  
Development Director  
Together for Short Lives

# Introduction

Evidence from the Independent Review of Children's Palliative Care Services<sup>1</sup> showed that there was inequity of service provision across England.

The Independent Review and the subsequent Labour government strategy for children's palliative care: 'Better Care: Better Lives' called for the development of strong commissioning networks and for a better understanding of local population needs. Evidence from research such as the ACT 'Voices for Change' report highlighted the family and professional perceptions of palliative care provision back in 2003<sup>2</sup>.

Children with life-threatening or life-limiting conditions and their families have complex needs that require a range of skills and services provided by a range of different organisations in health, social care, education and the voluntary sector. Care is provided by children's hospices, hospitals, and community services. With this huge range of services involved it is important that services work together to provide care for families in a joined up way and to avoid major gaps in service provision and poor transitions between services. There is also great potential for professional networks to enable better collaboration and partnership working between this multitude of providers.

Against this backdrop of policy and growing evidence, it was felt that the time was right to carry out a major research project to look at service provision as a whole, using one region of the UK to explore this issue in depth. The West Midlands region was chosen as the focus of this study as this is an area with strong networks, a variety of types of services and diverse ethnic communities. We believe

that our findings from this region will have the power to inform the provision of services not just in this area but also nationally, and will provide a good baseline to inform future work.

The overall aim of the Big Study was to answer the question "How well are the palliative care needs of children with life-limiting conditions and their families met by services in the West Midlands?" Within this aim, the Big Study had a number of objectives:

1. To identify the prevalence of need for palliative and supportive care within the West Midlands area.
2. To identify the extent to which services were perceived as family centred and the extent to which perceived needs were met both quantitatively and qualitatively.
3. To understand how professional networks both formally and informally supported the co-ordination, co-operation and collaboration of services.
4. To explore the costs of care to providers and families.
5. To facilitate involvement of parents, carers and young people in underpinning, advising and supporting the research.



1. Craft, A. and Killen, S (2007) *Palliative Services for Children and Young People in England: An Independent Review for the Secretary of State for Health*, London Department of Health.

2. Hunt, A., Elston, S. and Galloway, J. (2003) *Voices for Change: Current Perceptions of Services for Children with Palliative Care Needs and their Families*. Bristol: ACT.



## Part One

# How did we do it?

## Research design and methodology



This is the first in-depth study in the UK of how well the needs of children with life-limiting conditions and their families are being met. It is hoped that methods developed in this study will have applicability to future studies in other parts of the United Kingdom. Methods were informed through consultation with professionals and children and their families in the West Midlands during a development phase of the project which took place prior to the start of the main research project.

Five academic institutions were involved in undertaking the research, each focusing on different strands of enquiry.

### Recruitment of children, young people and their Families

The study took place from July 2011 to March 2012. In line with the original brief and Research Ethics Committee agreement, potential participants (affected children and young people and families including parents, legal guardians, family carers and siblings) were approached through Strand 1 invitation letters. Potential participants returned slips opting into other strands as preferred. Strand 2 also independently approached all the schools across the West Midlands and 29 agreed to take part and send out invitation letters to their pupils.

#### Strand 1

Understanding the demographic and geographical distribution of children with life-limiting conditions and their families  
University of Central Lancashire

#### Strand 2

Qualitative analysis of families' met and unmet needs  
Coventry University

#### Strand 3

A study of a professional network: Coordination, cooperation and collaboration across the West Midlands Paediatric Palliative Care Network  
University of Greenwich

#### Strand 4

An economic evaluation of service delivery  
York Health Economics Consortium

#### Strand 5

User involvement in the Big Study  
The University of Warwick

#### Strand 1

Researchers from the University of Central Lancashire undertook postal surveys of parents and service providers using the Measures of Processes of Care tool (MPOC and MPOC\_SP)<sup>3,4</sup> to evaluate the family and professional perceptions of the extent of family centred care being provided. An analysis of a minimum data set (MDS) was undertaken for children known to services in order to examine the demographics and epidemiology of the population of children with life-limiting conditions in the West Midlands.

3. King, S., Rosenbaum, P. and King, G. (1996) Parent's perception of care giving: development and validation of a measure of processes, *Child Care, Health and Development* 23 (1) pp.47-52.

4. Woodside, J.M., Rosenbaum, P.L., King, S. and King, G. (2001) Family-centred service: developing and validating a self-assessment tool for pediatric service providers, *Children's Health Care*, 30 (3), pp. 237-252.



## Strand 2

Appreciative Inquiry (AI) was chosen as the most appropriate approach to underpin Strand 2. Fundamental to this approach is the desire to discover 'what works well'<sup>5</sup> and 'why it works well'. AI has been used effectively within a variety of complex, organisational structures including health and social care settings<sup>6</sup>.

The research team from Coventry University conducted semi-structured one to one or focus group interviews in settings chosen by participants. These sessions used arts-based tools to ask participants what they felt was good about services (met needs); what could be better about services (unmet needs) and what their ideal services would look like in future.

Recruitment to Strand 2 of the study was very successful, with 66 families initially agreeing to take part. Of those, 51 families were then interviewed with in-depth interviews in the home setting or a focus group workshop as preferred. In total 59 individuals were interviewed and subsequently analysed.

## Strand 3

Researchers from the University of Greenwich carried out a study of the West Midlands Paediatric Palliative Care Network. All members of the Network were sent an email invitation to complete an electronic questionnaire about their involvement in the Network. An invitation to complete a paper copy of the questionnaire was offered at Network meetings, to all those who had not previously responded to the electronic questionnaire. The questionnaire was designed to find out what the network looked like and how membership of the network impacted on each individual, their professional practice and their organisation.

Those who had completed the electronic questionnaire were then invited to participate in a telephone interview. This provided more detailed information about relationships within the Network and gave a better understanding of how it operated and how it might be improved for the benefit of service users.

The data collected in the telephone interviews was recorded in a spreadsheet and analysed using the Social Network Analysis software tool 'R'. This allowed the network relationships to be displayed as a 'picture' showing the flow of knowledge, communication and information within the network.

## Strand 4

The York Health Economics Consortium (YHEC), carried out an economic evaluation of service provision. A subsection of the family questionnaire asked parents to estimate the additional financial costs to the family of caring for their children with life-limiting conditions. Similarly, a subsection of the service managers' questionnaire requested an estimate of the costs of providing healthcare to that population. NHS reference costs were used to estimate average costs for families and service providers where a cost was indicated but not quantified. They were also used to quantify the cost of inpatient and outpatient episodes, as well as the cost of diagnostic tests. The results were then extrapolated to build up a picture of costs across the West Midlands.

The second approach adopted to undertake the economic analysis was a review of the literature around the costs of caring for children with disabilities and life-limiting conditions and of the cost effectiveness of models of care for children with palliative care needs. The literature identified for this review came from a focused literature search, including previous and relevant studies undertaken by the team from YHEC.

## Strand 5

Researchers from the University of Warwick worked on an essential aspect of the Big Study – involving parents, children and young people in key stages of the project. The purpose of this involvement was to ensure that the study and its focus were relevant, acceptable and appropriate from the parents and children and young people's perspectives, so enhancing the quality and utility of the findings and contributing to the development of key messages from the study.

In addition, strand 5 of the study aimed to assess the impact of patient and public involvement within the study and to contribute to methodological development in understanding the difference user involvement makes to research.



5. c.f. Cooperrider, D. and Whitney, D. (1999) Appreciative Inquiry: a positive revolution in change. In *The Change Handbook: Group Methods for Shaping the Future*. Holman, P. & Devane, T. (eds.) San Francisco, Berrett-Koehler Publishers, pp 245-261.

6. Carter, B., Coad, J. and Goodenough, T. (2009) *Community Children's Nursing in England: An appreciative review of CCN's*. Department of Health Report. NHS at Home: Community Children's Nursing Services.



## Part Two

# What did we find?

## Headline findings



Headline findings from each strand are brought together in this section to portray a picture of the effectiveness of resources across the region in meeting the needs of children and their families. Please refer to the full research report to access the full findings from the project at [www.togetherforshortlives.org.uk/thebigstudy](http://www.togetherforshortlives.org.uk/thebigstudy)

### Strand 1

#### Understanding the demographic and geographical distribution of children with life-limiting conditions and their families

##### Findings from the Minimum Data Set

- 1180 children were identified who were living at the time the data was supplied. 131 children were identified who had died between 13 and 24 months previously.
- Over 50% of the children suffered from either congenital & chromosomal disorders or static encephalopathy, for example severe cerebral palsy. This figure was also reflected in the children that had died.
- Whilst the median age of living children was 8 years, the median age of children who had died was 3.5 years. However, the central 80% of children both living and deceased ranged from 1 to 17 years.
- While Office for National Statistics (ONS) descriptive statistics<sup>7</sup> suggest 15%-22% of all children in the West Midlands have a minority ethnic background, 37% of the MDS population of children identified by services were from ethnic minority backgrounds. Within these children, the largest ethnic minority group was South Asian (27%). In the Birmingham and Solihull cluster areas the proportion of the children in the MDS being from the South Asian ethnic group was nearly half (47%) whereas in West Mercia, the proportion was only 6%.

- Of the 883 postcode sectors in the West Midlands, the vast majority had a rate of between 1-10 children and young people with a life-limiting condition in every 10,000, though 75 sectors had rates of more than 20 children in 10,000. 5 sectors, at the Derbyshire border, Worcestershire border, and Shropshire border stood out as having a higher than usual rate.
- 24 families were living further than 20 miles from children's hospice facilities. Most of these were living in the Shropshire and Hereford area.

##### Findings from postal surveys

- Applying the Measures of Processes of Care tool, responses from the postal surveys were analysed and demonstrated that whilst on the whole families perceived their services to be offering respectful and supportive care and to be enabling, up to 50% of respondents rated certain elements of provision less highly. These included:
  - Provision of information specific to their child
  - Provision of general information about the availability of services
  - Provision of financial advice
  - Communication
  - Coordination between services
- Where parents had a named person to contact if they needed help and advice (a care coordinator) a higher rating of services was awarded.

7. ONS statistics – [www.nationalstatistics.org.uk](http://www.nationalstatistics.org.uk) by postcode sector (using boundary data from 2007) and postcode points for services (2006).

## Strand 2

### Qualitative analysis of families' met and unmet needs

#### Demographics of participants in family interviews

- All of the families interviewed lived within one of the five West Midlands NHS clusters or the Gloucestershire NHS cluster, with the highest proportion from Arden NHS cluster (41%) and Birmingham NHS cluster (25%).
- Of the total sample of children and young people, 36% of participants were in the 5-10 age banding; 15% were in the 11-15 age banding and 55% were male.
- The children and young people had a variety of conditions with 21% of conditions falling into the static encephalopathy and congenital & chromosomal groups whilst 19% had conditions within the neuromuscular group.
- Overall, 51% attended special school and 8% attended mainstream schools.

#### Met and unmet needs identified through family interviews

##### Family perspectives

- Families felt it was important to have trust and confidence in services and they wanted to receive high quality holistic care for their affected child and their whole family.
- Families attributed their ability to cope to various factors, such as being able to maintain a positive outlook, or drawing strength from their cultural or religious beliefs.
- Families spoke about how essential it was to be able to access respite or short break care to give them opportunities to take time away from round-the-clock caring duties.

- Being able to take part in social activities was difficult to arrange, but children and families enjoyed these activities and benefitted from services which enabled them to take time out in leisure pursuits, restore their sense of balance and experience a 'normal' family life.

*When he goes to [named hospice] he'll go around 4 o'clock on one day and then he'll spend all night there and all that day then all night again then I'll go pick him up again in the morning...gives me a good rest so I can sleep, do what I have to do then I'm ready again refreshed for when he comes back*

(Participant 12, Mother, Birmingham)

- Some parents also reported situations in which they had 'lost faith' in the quality of service provision when they felt it had impacted on their child's survival and recovery after an acute episode of bad health.

##### Services

- All of the parents and carers felt that every child and young person had the right to expect care to be provided at home and that hospital admission should be prevented or reduced to the minimum.
- Children's hospice services were also perceived as very beneficial to the family members who had used them.
- In general families felt that they had some choice, and that a high standard of service was delivered within their care package.
- Complex medical care packages were often planned and delivered by Community Children's Nurses (CCNs) and their support was rated very highly.

- The quality of support available within both special schools and mainstream education for children and young people with life-threatening and life-limiting conditions was varied, but there was overall agreement that provision of such support was important in meeting needs.
- Services that are provided 'under one roof' through schools (e.g. physiotherapy) were very useful for families.
- Families reported that the services that were most under pressure within the region were those that provided respite care and end of life care. Children's hospices were mentioned in particular as being under financial pressure.
- Many parents and carers reported that even within their PCT cluster areas, health, social and education services were not joined up.
- Respondents felt that responsive and modern systems should be in place to improve communication such as rapid mobile and bleep systems, and improved use of information technology across services so they did not have to keep repeating their story to different professionals.

##### Professional staff

- Children, young people and families valued the professionals they came into contact with (health, education and social care professionals) and often viewed them as confident, positive in attitude, competent, knowledgeable, dedicated, flexible, accessible, friendly and approachable. Many were cited as "going the extra mile" and were highly regarded for their part in providing family days or fun activities.
- Continuity and consistency of staff was important and firmly linked with familiarity, support and trust.
- CCNs were highly rated in terms of providing children and young people not only with excellent care, but also with opportunities to take part in normal activities with their families and peers.

- In many cases, families felt that a single port of call (one professional) could be ideally placed to listen to them and support their needs.

##### Communication

- Good communication and being listened to is valued by children and their families, but in all the regional areas studied, participants reported having had to repeat their 'stories' many times because coordination within and between service providers was often poor.
- Collaboration and communication between services was often felt to be fragmented but there were examples of where it did work well in the community, for example between school nurses; paediatric and community consultants; community nurses and special schools.
- Participants were generally well informed about how health, education and social care delivery should be jointly planned and delivered in partnership with service users. The perceived lack of such multi-disciplinary and multi-agency working with service users was seen as a pivotal failing.

*It is like banging your head against a brick wall. None of the doctors ...speak to the other - they all do their own thing and that's it*

(Participant 37, Mother, Arden)

- A large number of families said that they would like more opportunities to communicate with other families who were in similar circumstances, including through internet based social networking.
- Across the NHS cluster areas, the availability of information was found to be varied, with easily accessible information being the exception rather than the rule.



### Strand 3

#### A study of a professional network: Co-ordination, cooperation and collaboration across the West Midlands Paediatric Palliative Care Network

- The initial social network analysis suggested that this network was densely connected, with a core and periphery structure. It appeared relatively decentralised with many people being seen as sources of advice, leadership and influence.
- The results of the questionnaire showed that the network had grown by over 50% in the last few years although 15% had been members for between 7 and 12 years.
- The network membership is largely composed of nurses (58%) and doctors (30%) working in the NHS (60%), but 15% and 18% respectively work for hospices and other charities.
- Key benefits that members derived from the network included obtaining new ideas to improve practice, access to resources, new professional relationships, an increased sense of efficacy and ability to represent service users.
- Only a tiny minority felt that service users did not benefit from the network or that the network limited the members in some way, such as the additional time commitment.
- The majority of members felt that they had contributed to the network.
- Members also perceived that the network and its subgroups had delivered improvements, for example, through developing resources such as tools for improving care, and successfully bidding for research funding.

### Strand 4

#### An economic evaluation of service delivery

- The literature review demonstrated that there have been very few economic studies of models of care for children and young people with life-limiting conditions.

##### The financial burden for families

- Caring for children and young people with life-limiting conditions imposes considerable costs on families and carers and they have to bear many hidden costs of care which would otherwise significantly increase the cost to the State.
- Families have to bear additional costs totalling on average over £1,400 per year for a range of everyday and recurring items such as food, clothing, travel and heating.
- Families also have to pay less regular but more expensive costs such as housing and vehicle adaptations. Survey respondents reported having spent on average over £7,400 on such things over the course of their child's life – in some cases this figure was nearly £200,000.
- As well as the additional costs to families, many have had to reduce or give up employment, losing an estimated £6.4 million per year across the West Midlands. This equates to an average of nearly £5,500 in lost income per family every year, though some families have claimed additional benefits to offset this loss.

### The cost to public services

- Respondents' costs for hospital-based care were estimated to be on average over £7,100 per family per year. This equates to an overall cost for the West Midlands of around £8.4 million per year.
- Non hospital-based care costs, including those associated with community children's nursing teams, GPs, clinical psychologists and allied health professionals (physiotherapists, speech and language therapists and occupational therapists) came to an average of over £1,100 per family per year, or approximately £1.3 million across the West Midlands.
- The cost of short breaks for families in the West Midlands was estimated at nearly £3.7 million per year across the whole region, or over £3,100 per family.



### Strand 5

#### User involvement in the Big Study

- The Parents and Carers', and Children and Young People's Advisory Groups had a clear impact on the Big Study. This was especially important during the later stages of the study, particularly in the interpretation of data and the identification of priorities for action.

*"Involvement matters: Research should make a difference. Involving children, young people and parents throughout studies, including making use of findings, can be key to making this happen."*

**Recommendation from the Parent and Carer Advisory Group**

*"Families need help, not hurdles: Family-centred support needs to be co-ordinated, from the time of diagnosis to bereavement and beyond, so that families can better carry out their central role in caring for a child or young person with a life-limiting or life-threatening condition."*

**Recommendation from the Parent and Carer Advisory Group**

- The research identified context and process factors of importance to patient and public involvement, so that the research team were able to better understand what matters to parents and to children and young people taking part, and to appreciate the varied perspectives of researchers working on the Big Study.

## Part Three

# What does better care for children, young people and their families look like?



Qualities of better care from findings across the Big Study

From the analysis of findings from the Big Study, it is possible to group elements of what 'better care' may look like under the following eight headings.

### Communication and information

- All families have equal access to information and advocacy services.
- Communication with children and young people is valued and opportunities are provided to enable them to talk with a trusted professional.
- Improved communication training is available for professional staff including how to communicate sensitive information.
- A greater emphasis is placed by services on the communication of information and end of life planning with children, young people and their families.
- Information is clearly provided about the roles of different professionals.

### Costs

- Financial support is equitably and fairly assessed to relieve the financial burden on families.
- Provision of financial advice to families becomes an essential component of a children's palliative care service, available from diagnosis and into bereavement.
- Robustly calculated and resourced commissioning models are in place, so that sustainable funding is available to support services to meet the needs of children and families.
- More research is underway looking into family costs, including one-off expenses and costs for families associated with bereavement.

## Coordination of care

- Children, young people and families have access to age appropriate services, whether in relation to education, social care or healthcare.
- There is good and timely planning for the transition from children's into adult services.
- More care is available on a 24/7 basis, with quicker and smoother access to services.
- Better coordination and communication between services enables improved transitions between hospital, hospice, home and other services.
- Families have a named individual to help them navigate the system to enable access to the appropriate services in a timely manner.

## Collaboration and cooperation

- A fully integrated multi-disciplinary and multi-agency service is in place across the whole region.
- Improved communication within and across health, education and social care teams ensures that all providers are fully informed, up to date and working from the same information, for example using shared databases across agencies.
- Resources are shared across the region to enable the provision of sustainable specialist and emergency care.
- Services work in partnership so that families have choice and flexibility over their place of care, place of death and provision of short breaks.
- Children's palliative care networks include representation from all health, social care, education and third sector organisations providing services to children needing palliative care.
- There is two-way communication between children and families and the children's palliative care professional networks.

## Centred on children, young people and families

- The expertise of parents is respected and strengthened.
- Services are age-appropriate and centred on children's, young people's and parental choice and take account of what is important to each individual child or young person and their family.
- Life-long care packages are in place, which meet the needs of the child or young person and families, and are delivered by competent, trained carers.
- The centrality of the family's role in caring for a child with a life-limiting or life-threatening condition is recognised, with support needs met for the whole family.
- Parents, children and young people are encouraged to actively participate in research studies, with feedback given or action taken on their views.



## Caring for wellbeing

- A regional service meets not only the physical needs but also the emotional, counselling and psychological needs of children, young people and families, starting at the point of diagnosis and into bereavement for the family.
- Opportunities are provided to enable children, young people and families to take short breaks and holidays.
- Equipment is provided in a timely and efficient manner to enable families to function as 'normally' as possible in their home.
- Opportunities are provided for families to make contact with other families in a similar situation.

## Commonality and equity

- Every child or young person has access to care services in their region, that operate on a 24/7 basis and which are accessible, fair, comprehensive and flexible as their needs change. Improved regional delivery in respect of specialist speech and language therapy, physiotherapy and occupational therapy is available.
- Every child or young person has access to the right school and to the right service to meet their educational needs regardless of where they live.

## Competency and confidence

- Services ensure there are skilled, trained carers to meet the needs – including comprehensive symptom management – of children, young people and families.
- Professional staff (within health, social care and education) have improved skills, competency and confidence to care for and support children and young people with life-threatening/life-limiting conditions and their families.



## Part Four

# What are the recommendations for the future?



The following recommendations have been identified as priority actions to be taken by service providers in light of the Big Study findings:

1. There needs to be continued emphasis to improve the quality and quantity of information for families, with clarity about whose role it is to provide the required information.
2. Provision of financial advice and support to families should be seen as an essential component of a children's palliative care service.
3. Families should be supported through a model that provides navigation and coordination of support.
4. There needs to be continued emphasis to improve collaboration and joined up communication within and across health, education and social care teams.
5. Recognition should be made of the family's central role in caring for a child with a life-limiting or life-threatening condition. Providers of services must listen to the views of children and young people with life-threatening and life-limiting conditions and their families in order to ensure that their needs are reflected when providing a quality service.
6. Services need to ensure they provide a range of support to meet the family's emotional and psychological needs, from diagnosis to bereavement.
7. Professional staff working across health, social care and education need to ensure they continue to improve their skills and competency relevant to children and young people with life-threatening or life-limiting conditions and their families.
8. Children's palliative care networks establish sub-groups to focus on improving transition and service integration at an operational level.

### Next steps for Together for Short Lives

Together for Short Lives is committed to sharing the findings of the Big Study with a wide range of stakeholders. We plan to use the findings of the Big Study to inform our lobbying and campaigning on behalf of all children and young people with life-limiting or life-threatening conditions and their families.

Some of the findings of the Study have highlighted specific areas of activity or further research that we will consider for inclusion in our current or future strategic plans.





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