The

Big Study

for Life-limited Children and their Families

Final research report

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/bigstudy

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Foreword

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

The initial idea for the Big Study came about at least five years ago at a Board meeting. 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 idea to fruition.

The Big Study has been a complex study with many partners through its two year duration. Those involved in such studies 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 project manager, Julia Hodgson, the Big Study has delivered its findings and we were able to work with 1180 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 rich data.

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 co-ordination 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 need for short breaks and support for parents, carers and siblings must be provided to balance 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 of this research to inform its future activities and campaigns, and plans to continue to work on developing 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 strong and we look forward to working with some of the families from the Big Study in our future work.
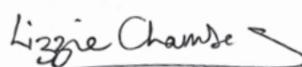
Lizzie Chambers

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Development Director
Together for Short Lives

Full research findings (PDF) for each part of the Big Study and an overview document are available from
www.togetherforshortlives.org.uk/bigstudy

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Strand 5: Inclusion of service users and participation across the study

The Big Study map

Map of the study area showing the West Midlands boundary (blue) and the boundaries of the health authorities
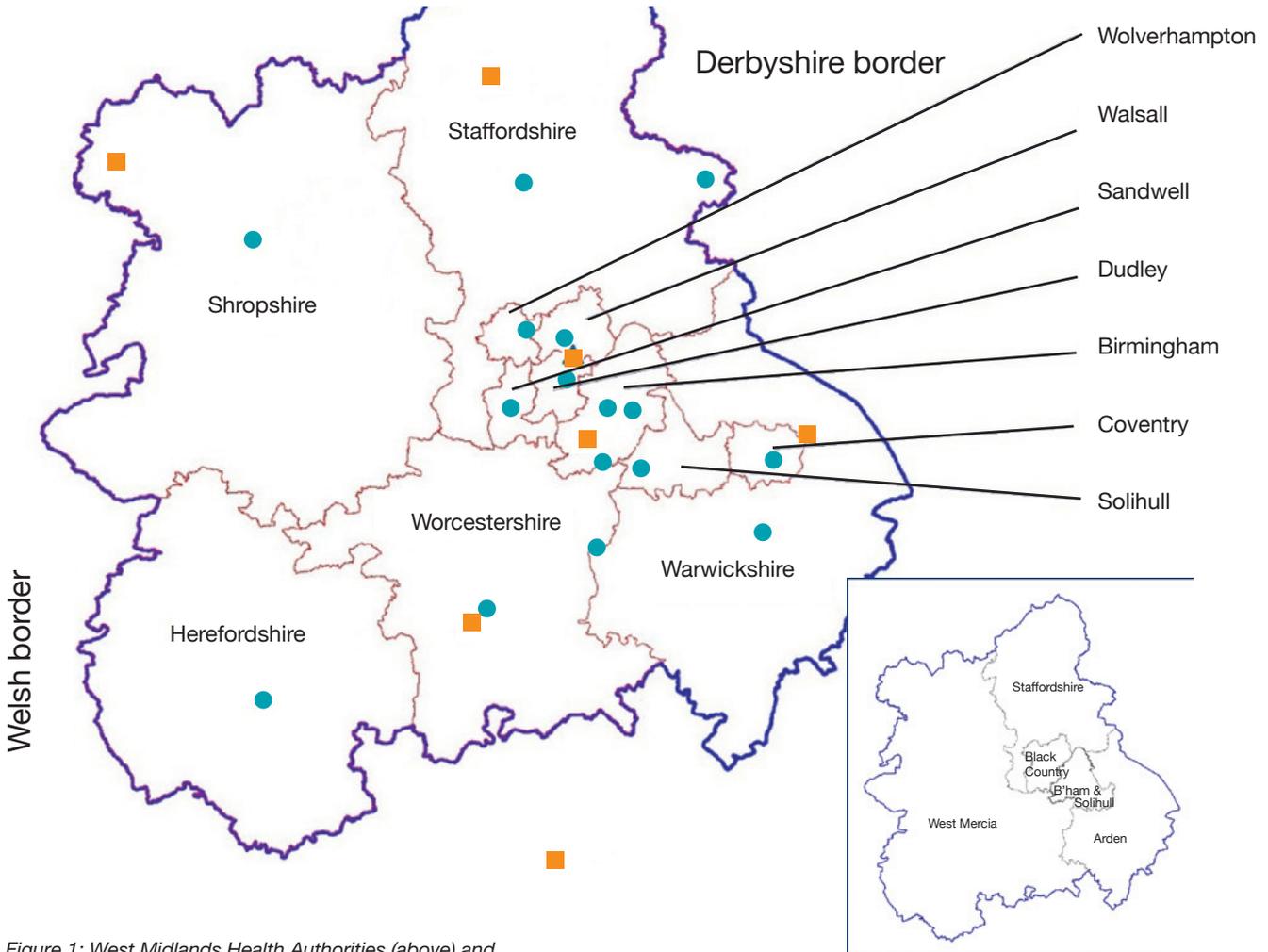
Figure 1: West Midlands Health Authorities (above) and Primary Care Trust (PCT) clusters (to the right)

● **Participating centres for the Big Study (other than Children's Hospices)**

■ **Children's Hospices within 20 miles of the boundary**

Shropshire	–	Hope House
Staffordshire	–	Donna Louise Trust
Walsall	–	Acorns
Worcester	–	Acorns
Birmingham Selly Oak	–	Acorns
Coventry	–	Zoe's Place
Oxford	–	Helen House

Background

Children with life-limiting and life-threatening 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.

When services and agencies work independently and in isolation, care can be fragmented. Seamless care, by comparison, requires effective communication, co-operation and collaborative partnerships across organisations (Hunt, Elston, & Galloway, 2003). Hospices, hospitals, and community services are all involved in caring for children with life-limiting conditions. Children and young people will often move from one setting to another as their condition changes and, as they grow older, young people may transfer from children's to adult services, a transition that requires careful negotiation (Watson, Parr, Joyce, May, & Le Couteur, 2011). Overall, care is generally provided by parents in the child's home. It is very important that the quality of services is reviewed to be certain that wherever possible families are getting the care and support they need.

The economic study (YHEC, 2007) undertaken to support the Independent Review of Palliative Care Services for Children and Young People (Craft & Killen, 2007) identified variation in delivery of services, in availability of community based services, and the number of children being managed in hospital settings. There was also great variation in the proportion of children dying at home, usually considered to be families' preferred place of care.

The timing of the research reported here was linked to the publication Better Care: Better Lives (DH, 2008), the government's strategy for children's palliative care. The strategy called for the development of strong commissioning networks and better understanding of local population needs.

In relation to the better understanding of local population needs, some limited studies have been conducted, for instance, Voices for Change (Hunt et al., 2003), Providing a seamless service for children with life-limiting illness (Danvers, Freshwater, Cheater, & Wilson, 2003), and Evaluation of the Big Lottery Fund Palliative Care Initiative (Carter, 2006). The Big Study is believed to be the first in-depth study in the UK of how well the needs of children with life-limiting conditions and their families are met across a single region.

Twenty one service centres, both NHS and non-NHS, participated. These Participant Identification Sites provided information to the study teams on over 1,000 children with life-limiting or life-threatening conditions and their families in the West Midlands region.

Research design and methods

Aims and objectives of the study and work programmes undertaken

The questions we aimed to answer were:

- How well are the needs of children with life-limiting conditions and their families being met by supportive and palliative care services in the West Midlands?

- Under what local conditions are children's and families' care needs better met?

- What are the distinctive characteristics of professional paediatric palliative care networks in the West Midlands that may explain areas of strength and weakness in operation?

- What are the costs of providing services that meet the needs of children and families?

- What was the impact of user-involvement on the research?

Data collection and analysis was carried out between July 2011 and June 2012.

Data consisted of:

1) A minimum data set (MDS) of children known to services.

2) Questionnaire responses of parents, staff and service managers.

3) Qualitative in-depth participatory interviews and focus groups from children, parents and carers.

4) Structured interviews with staff and service managers.

5) Comparison data from national statistics and NHS sources.

Work was divided between the participating research teams under five strands:

- **Strand 1: Surveys and geographic analysis: Identifying the prevalence of need**

- **Strand 2: Understanding the met and unmet needs of children and families**

- **Strand 3: Understanding how professional networks support services**

- **Strand 4: Economics and costing: Exploring the costs of care to providers and families**

- **Strand 5: Facilitating the involvement of parents, carers and young people**

Strand 1

Identifying the prevalence of need – through analysis of a Minimum Data Set (MDS) and surveys of parents, staff and service managers

Minimum Data Set (MDS)

We asked services supporting children with life-limiting conditions to provide a minimum data set (MDS) for all children known to their service with a life-limiting condition. The MDS consisted of five items of basic demographic data (age, gender, ethnicity, partial postcode excluding the last two digits and diagnosis). The protocol approved by the Local Research Ethics Committee (LREC) and National Informational Governance Board for Health and Social Care (NIGB) required that parents were offered the opportunity to opt out. Parents were informed in a letter distributed with the parent questionnaire that they should let their service know within four weeks if they did not want their child's MDS to be provided to the researchers.

Disease group

Children were allocated to a disease group as categorised in Table 1 (p.12).

Analysis of MDS

The demographic data from the MDS was examined in relation to geographical areas of deprivation, ethnicity, and distance from services[1].

We asked the Parent Carer Advisory Group to name an acceptable distance to travel in order to access hospice services. A distance of 20 miles was agreed upon, acknowledging that this very much depended on reasonable journey duration. In order to estimate appropriate access to children's hospices, we drew a circle with a radius of 20 miles around each of the children's hospice sites including two that were outside the West Midlands area (Loughborough and Oxford). Oxford fell within the boundary but Loughborough did not.

Demographic and other analyses were by PCT cluster areas which contain the health authority boundaries. These were used rather than postcode sectors because small numbers might have distorted comparisons. Geographic analysis used smaller health authority areas for comparison within clusters.

Survey questionnaires and instruments

Four questionnaires were designed for distribution to parents, bereaved parents, service staff and service managers.

Parent questionnaire

This requested demographic information about the child and family. It included a slightly adapted version of the 56 item Measures of Processes of Care (MPOC-56) (King, Rosenbaum, & King, 1996) and a list of met and unmet needs. This list was derived through consultation with users and providers held prior to the Big Study, from the literature and from the professional experience of the researchers.

The MPOC-56 (King, Rosenbaum and King 1996) was developed as a measure of parents' perceptions of the extent to which the health service they and their child receive is family-centred. The MPOC-56, distributed by the CanChild Centre for Childhood Disability Research, McMaster University in Canada, is widely used in children's disability and rehabilitation services and has good validity and reliability (King, Rosenbaum, & King, 1997). The MPOC-56, with minor changes, was used to evaluate children's disability community services in the UK (McConachie & Logan, 2003), and in an evaluation of a children's palliative care service in York (Whitton, Williams, Wright, Jardine, & Hunt, 2008). A shorter version, the MPOC-20, has been developed (King, King, & Rosenbaum, 2004). We chose to use the longer version as there is currently limited data on use of these measures in children's palliative care services. Each of the 56 items is presented under a common question: 'To what extent do the people who work with your child (for example …take the time to get to know you and your child?)'. A seven point scale was used, from (1) 'Never', to (7) 'A great extent'.

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1. We used postcode sectors and the 2001 Health Authority areas rather than existing 2009 PCT areas. At the time, the 2009 PCT areas were in the process of combining in to cluster areas (2012) but information was not readily accessible on the Geographical Information System borders for these cluster areas. However, Health Authority boundaries (2001) can be combined easily to form the new PCT cluster areas.

There is no total score. Analysis of each respondent's data yields five scores, one for each of five factors or scales, these five factors are:

• Enabling and partnership

• Providing general information

• Providing specific information about the child

• Co-ordinated and comprehensive care for the child and family

• Respectful and supportive care

A score for each factor is obtained by computing the average score for the items belonging to that factor. The MPOC Manual details which items make up each factor and the management of missing items.

Bereaved parent questionnaire
This was similar to the above but did not include the MPOC scale.

Staff questionnaire
The questionnaire included the Measure of Processes of Care for Service Providers (MPOC-SP) (Woodside et al., 2001).

The MPOC-SP is a well validated tool and has been used in a variety of settings (Dyke et al., 2006; Pickering & Busse, 2010; Woodside et al., 2001) including children's palliative care (Whitton et al., 2008) to help professionals reflect on their own practice. The MPOC-SP assesses whether the organisations perceive themselves to be delivering family-centred care on four dimensions. The presentation of the MPOC-SP was slightly adapted for the study but no changes were made to the items.

The four factors are:

• Showing interpersonal sensitivity

• Providing general information

• Communicating specific information about the child

• Treating people respectfully

In addition to the MPOC-SP, participants were asked to what extent they thought that specific needs of families and children in the service they worked for were being met on a seven point Likert scale (1 – 7, from (1) 'not at all' to (7) 'more than needed').

Free text within questionnaires
On the final page of the parent, bereaved parent and staff questionnaires there was an opportunity to identify three things they would change about the services received or provided. In addition, parents were asked what might make (or has made) the biggest difference to the quality of their family life.

Service manager questionnaire
The service manager's questionnaire asked more generally about the area covered by their service, levels of staffing, funding, limitations in their service and ambitions for the future.

Analysis of questionnaires
Averages are reported as mean and standard deviation (sd), and as median when data was skewed. Differences between groups were explored using t-tests and analysis of variance. Chi-square tests were used when examining differences between observed and expected proportion by PCT Cluster area.

Grouping of life-limiting conditions of children included in The Big Study

Children's conditions were categorised by ICD10 and then further into disease groups that would be meaningful for practitioners.

Table 1: Categorisation of children's life-limiting and threatening conditions

Disease group	Description of conditions included in disease group	ICD10 codes
Congenital and chromosomal	Includes children with chromosomal conditions such as Downs, Pattau, Edwards Syndromes and other less common abnormalities. Also children with congenital abnormalities of the central nervous system such as lissencephaly, hydrocephalus, microcephaly. Also children with congenital heart disease, short bowel, biliary atresia.	Mainly Q codes. (Congenital malformations, deformations and chromosomal abnormalities) Some K codes (Diseases of the digestive system).
CNS Static encephalopathy	Non-progressive CNS disease including cerebral palsy, developmental delay and epilepsy. Brain injury, Birth asphyxia, Hypoxic ischaemic encephalopathy.	Mainly G codes (Diseases of the nervous system). Some P codes (Certain conditions originating in the perinatal period) e.g. 'Brain injury'/'birth injury', 'hypoxic ischaemic encephalopathy'.
CNS progressive	Disease often categorised as 'Progressive Intellectual and Neurological Deterioration (PIND)' characterised by loss of skills. Includes children with mucopolysaccharidoses (Hurlers, Hunters, Sanfilippo), lipofuscinosis (Juvenile, Late infantile and Infantile Battens), leucodystrophies (Adrenoleucodystrophy, metachromatic leucodystrophy, Krabbes), Retts, Juvenile Huntington's. Most conditions in this group are inherited as single gene and/or mitochondrial disorders.	Mainly E codes (Endocrine, nutritional and metabolic diseases). Some G codes (Diseases of the nervous system).
Neuromuscular	Duchenne muscular dystrophy, Spinal muscular atrophy, Congenital muscular dystrophy, Ataxia telangiectasia. Friedreich's ataxia. These are also inherited as single gene recessive or x-linked conditions or as mitochondrial disorders.	Mainly G codes (Disease of the nervous system).
Cancer	Solid tumours, Brain tumours, Cancer of blood and lymphatic systems.	C codes (Neoplasms).
Pulmonary and respiratory	Cystic Fibrosis (single recessive gene disorder), Chronic lung disease (sometimes resulting from prematurity)	Cystic fibrosis E 84.9. Chronic lung disease J98.4.
Other	Endocrine and renal disorders. Immunodeficiency. Trauma (for instance due to road traffic accident).	B & D (Immunodefiecency), E (endocrine), K (digestive), M (musculoskeletal), N (genitourinary), S & T (Injury and trauma).

Strand 2

Identifying the extent to which needs were met through interviews with children and families

Recruitment for interviews
Lead collaborators at participating centres identified the families by screening the service records to identify eligible children and families for the study. Service providers distributed the surveys to families and staff within a protocol approved by LREC and NIGB. In line with the original brief and Research Ethics Committee agreement, potential participants (affected children and families including parents, legal guardians, family carers and siblings) were approached through Strand 1 invitation letters that accompanied the family surveys. Potential participants returned slips opting into strands as preferred including Strand 2 to be involved in further activities such as arts workshops, advisory groups and interviews. Strand 2 also independently approached all the schools across the West Midlands and 29 agreed to take part and send out invitation letters. The inclusion and exclusion criteria were set for Strand 2:

Inclusion criteria
- 50-80 families using West Midlands Children's Services.

- Families living in one of five West Midlands NHS clusters and Gloucestershire NHS Cluster (n=6).

- Children with a diagnosis of a life-limiting or life-threatening condition and their families that are receiving children's palliative care services.

Exclusion criteria
- Families not using the services of West Midlands Children's Services.

- Families not living in the West Midlands NHS clusters or Gloucestershire NHS Cluster.

- Young adults not in receipt of children's palliative care services.

The West Midlands has a number of diverse ethnic communities. The research team worked with each participating centre to ascertain the main languages spoken in their area. The approach letters to parents and carers provided translation boxes for Gujarati, Urdu, Bengali, Punjabi, Arabic and Mirpuri indicating language support was available from a UK language translation service once a week for two hours, throughout the time of the questionnaire distribution.

Interviews and focus groups
To identify met and unmet needs of children and their families, in-depth interviews and arts-based focus groups were conducted using an Appreciative Inquiry (AI) approach. This was chosen as the most appropriate approach to underpin Strand 2. Fundamental to this approach is the desire to discover 'what works well' and 'why it works well' (see for example, Cooperrider and Whitney, 1999). Appreciative Inquiry has been used effectively within a variety of complex, organisational structures including health and social care settings. Appreciative Inquiry lends itself well to a pragmatic approach which was felt to have a good fit within the current study. Settings were chosen by participants and participants were asked using arts-based tools what was good about services or met needs, what could be better about services or unmet needs and what the ideal future for services would look like.

Analysis
Open ended questions from the questionnaire were analysed thematically. Principles of framework analysis were used to analyse the data. Once all data sets were coded, initial categories were refined and sorted into three main sub-categories within the themes of met needs, unmet needs and implications for future needs.

Strand 3

Questionnaire and interviews with professionals to understand how professional networks support services

Recruitment
All members of the West Midlands Paediatric Palliative Care Network (WMPPCN) and the organisations they represent were invited to participate in the study. The study did not include any of the other networks, e.g. children's speciality networks or networks covering smaller geographical areas, to which members belonged. An electronic questionnaire was distributed to members through the network to obtain information about the benefits and constraints of the network. Members were invited to participate in semi-structured additional telephone interviews to provide more detailed information about professional networks. This data was collected during the period February to June 2012.

Analysis
Descriptive statistics were used for the quantitative aspects and a thematic framework was developed for the open ended questions in the survey. Telephone interviews were analysed using social network analysis methods (NHS, 2005) to explore the flow of knowledge, communication and information within the network.

Strand 4

Exploring the costs of care to providers and families through questionnaires and literature review

Recruitment
A subsection of the family questionnaire asked parents to estimate additional financial costs to the family of caring for their child. Similarly, a subsection of the service manager questionnaire requested an estimate of the costs of providing healthcare to that population.

Costing methods
Data was collected from 188 families of children with life-limiting conditions in the West Midlands. A considerable amount of data was collected on the economic burden of looking after children with life-limiting conditions, including:

- One-off costs such as equipment or wheelchairs.

- Ongoing annual costs to parents such as heating or travel.

- The additional costs to families of caring for children and young people with life-limiting conditions, including any income lost as a result of having to reduce or give up employment.

- The costs of healthcare, including primary, community and acute care, over a period of six months.

Diagnosis
The economic analysis used the study diagnostic categories (Table 1, p.12) to collate the costs for the children whose families returned the survey.

Income
A national estimate of average earnings was applied to the amount of working time respondents stated that they and their families had lost. No account was taken of any additional benefits that families receive to support their care activities or loss of employment. Median costs were calculated to help quantify costs where data was incomplete or unknown. Nationally available cost data for healthcare resources were used to estimate the costs of healthcare.

Public services

The public service cost estimate was calculated from parents' reports over six months of the number and type of:

- Admissions and outpatient visits to hospital

- Diagnostic tests

- Visits to or by community, social and voluntary care professionals

- Short breaks for the child

Median costs were chosen over mean costs because of the large range reported.

Overall cost estimates for the West Midlands

The results were extrapolated to build up a picture of costs across the West Midlands, using the ICD10 and diagnostic categories for all the families surveyed (Table 1, p.12). These aggregate numbers were then used to extrapolate the wider costs to families in the West Midlands, based on the survey findings.

In addition to the costing work, 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 was carried out. The literature identified for this review came from three sources:

- A focused literature search. Titles and, where available, abstracts of all literature identified were examined, from which studies which addressed costs of services, costs of managing disabled children, burden on families and economic studies were selected.

- Previous and relevant studies undertaken by the team from YHEC were re-examined and findings within or relevant literature were included.

- Snowballing; identifying relevant titles from bibliographies or the body of articles identified from the above methods.

Strand 5

Facilitating the involvement of service users

Recruitment

A Parent Carer Advisory Group was established consisting of parents and carers who had volunteered their contact details during the planning stages or in response to the questionnaire and information sheets. Core group members were paid a sum to represent four or five hours of time to support their involvement in the study[2] and also paid expenses.

Methods

Parents and carers participated and contributed in a range of ways, through bi-monthly meetings, via email contact and attending steering group meetings. They were asked to comment on methods and emerging results and to consider their own participation in the study using reflective diaries. Children and young people were involved in interpreting, commenting on, illustrating and prioritising the issues raised by family members on changes in services they would like to see. A content analysis explored the impact of patient and public involvement within the study.
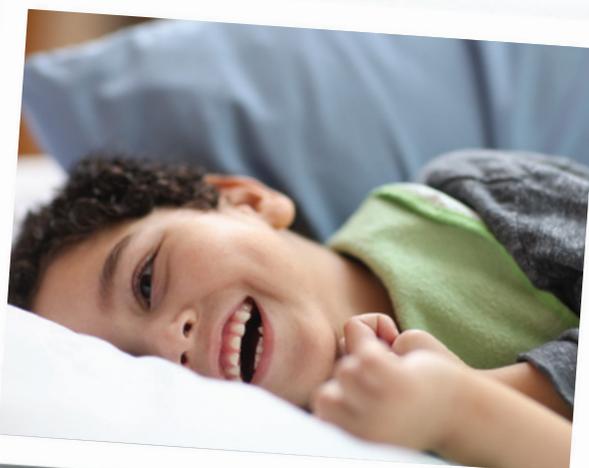
The Big Study findings

Strand 1: Identifying the prevalence of need

1a) Response and numbers of children identified through analysis of MDS

Twenty one services contributed basic demographic information (the MDS) about children known to them. 1180 living children were identified at the time the data was supplied. 131 children who had died 13 to 24 months prior to April 2011 were also identified (10% of the total of 1313). It could be expected that a further 150 children may have died from a life-limiting condition in the year to end April 2011.

Numbers of children were mapped to postcode sectors (the first four digits of the postcode) to show distribution and identify particular small areas of high density (figure 2) and then mapped onto 2001 Health Authority boundaries to provide information useful for planning and commissioning (figure 3). Darker colours indicate more children in the area. No colour indicates none.

Analysis by postcode: Figure 2 shows an analysis of the number of children by postcode sector. There was a wide variation across these small areas ranging from 0 to 17 children and young people in each sector. Eleven (2%) out of 502 postcode sectors (within the West Midlands boundary shown) contained 10-17 children, whereas 109 (20%) postcode sectors had no reported children at all.

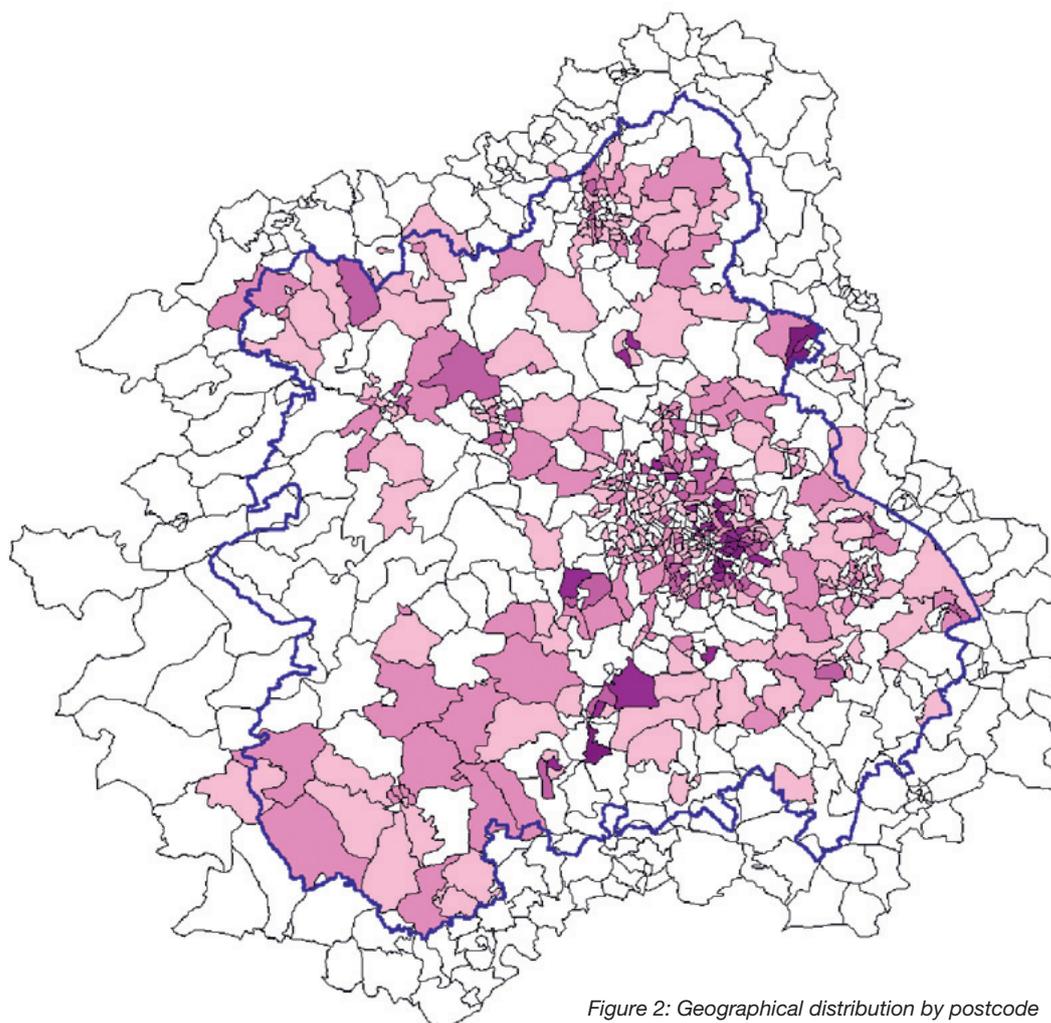| Low to high Density	Number of children per postcode sector	Postcode sectors (n)
	10 to 17 (High density)	11
	6 to 10	27
	4 to 6	49
	2 to 4	110
	1 to 2 (Low density)	196
	0 (None)	109
Total number of postcode sectors		**502**

Figure 2: Geographical distribution by postcode sector of children with life-limiting conditions over the West Midlands

Colour	Density of children per Health Authority	2001 Health Authorities
	433 (High density)	Birmingham
	100-200	South Staffordshire, Worcestershire
	80-100	Warwickshire, North Staffordshire, Shropshire
	60-80	Walsall, Dudley
	40-60	Sandwell, Wolverhampton, Coventry
	37-40 (Low density)	Herefordshire, Solihull

Total number of postcode sectors	13
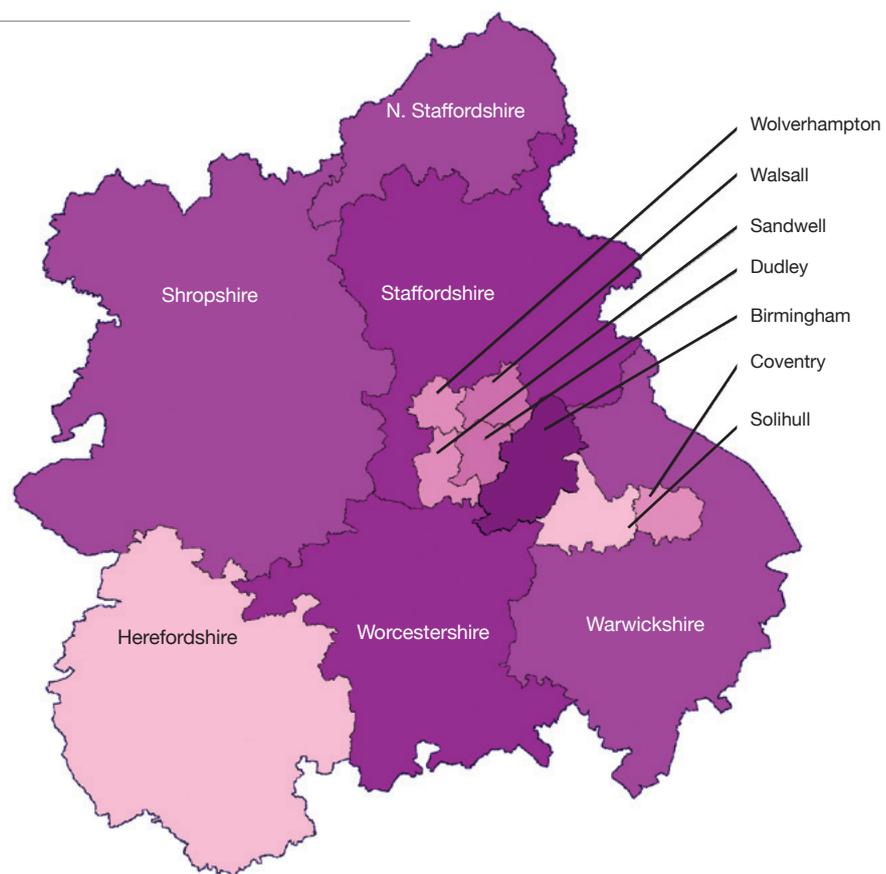
Figure 3: Geographical distribution by Health Authority of children with life-limiting conditions over the West Midlands

Analysis by Health Authority: Figure 3 shows an analysis of the numbers of children in each Health Authority. The Birmingham Health Authority contained the most children with life-limiting conditions; there were 433 children reported. In contrast, services in Herefordshire and in Solihull each reported only 37-40 children.

Prevalence rates

To compare prevalence between different areas (some areas were more densely populated than others), rates were calculated per 10,000 children (2011 Office for National Statistics (ONS)). Birmingham had the highest rates of children with life-limiting or life-threatening conditions, at 16 children per 10,000. The rates for Sandwell and Coventry were lowest at 4-6 per 10,000 (Table 2).

The overall prevalence across the West Midlands region was 8-10 children per 10,000.

Table 2: Rates of children with life-limiting conditions per 10,000 children by Health Authority

Rates per 10,000 children	Health Authorities (2001 boundaries)
16	Birmingham
12	Worcestershire
10-12	South Staffordshire
8-10	Walsall and Herefordshire
6-8	Shropshire, North Staffordshire, Wolverhampton, Dudley, Solihull and Warwickshire
4-6	Coventry and Sandwell
8-10	**Overall Rate**

Age groups of children with life-limiting conditions
The median age of children identified from the MDS was eight years with a range of 0-30 years old. However, the central 80% of children ranged from 1.6 to 17.3 years. The proportion of young people over 18 was 8%. The median age of children who had died was 3.5 years (with a range of 0 to 25 years).

Ethnic background of families

Figure 4: Percentage of children from ethnic minority backgrounds with life-limiting conditons identified by the Big Study (left) compared with general population (ONS 2011) statistics (right)

BiG Study children
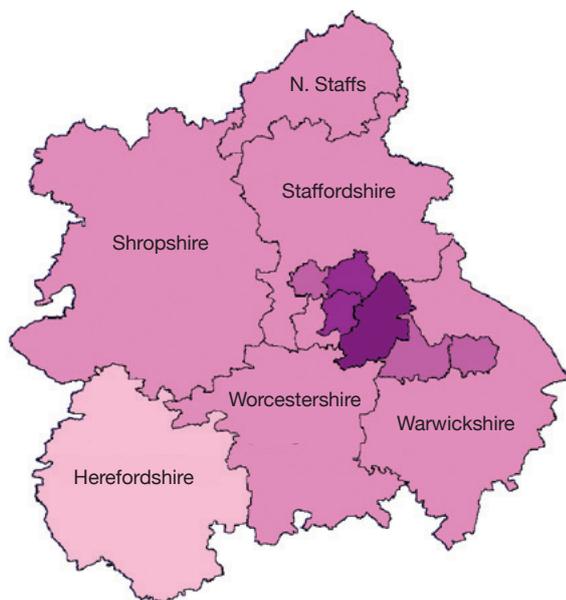
All Children in West Midlands
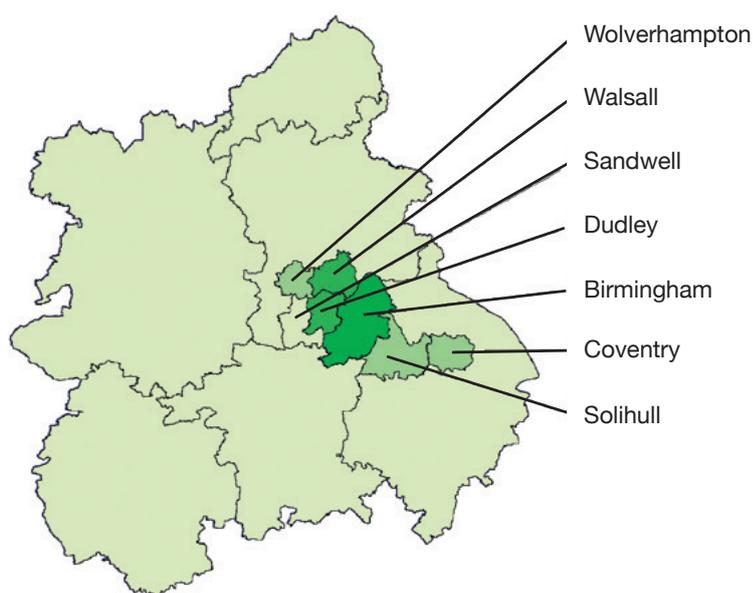
Percentage of children from ethnic minority backgrounds with life-limiting conditions

	Range	Area
	60-70	Birmingham
	40-60	Walsall, Dudley, N. Staffs
	20-40	Staffordshire, Wolves, Walsall, Solihull, Coventry
	0-20	Shropshire, Herefordshire, Warwickshire, Worcestershire

Percentage of all children from ethnic minority backgrounds (ONS 2011)

	Range	Area
	21-22	Birmingham
	20-21	Walsall, Dudley
	19-20	Wolverhampton, Solihull, Coventry
	17-19	Shropshire, Stafforfshire, N. Staffs, Sandwell, Herefordshire, Warwickshire, Worcestershire

The ONS suggests 17%-22% of all children in the West Midlands come from a minority ethnic background (Figure 4, right hand side). In contrast, 37% of the MDS population of children identified by services were from ethnic minority backgrounds (Table 3). In Birmingham and district, ONS statistics suggest 22%, whereas the MDS identifies 68% of the Big Study population has minority ethnic backgrounds (illustrated darkest on the map, Figure 4, left hand side).

The largest ethnic minority group in the study was South Asian (27% compared with the general population proportion of South Asian children 0-15 years, of 14% over the West Midlands, ONS 2011). In the Birmingham and Solihull cluster area the proportion identified by the MDS was nearly half (47%, Table 3) whereas in West Mercia the proportion was only 6%.

Table 3: Ethnic background of children and young people by PCT cluster area in which they live

PCT cluster area comprising Health Authorities shown	White British and Irish %	Asian and British Asian %	Black and Black British %	Mixed %	Other %	Not known %	Total 100%
Arden (Coventry and Warwickshire)	75	14	2	4	6	0	124
Birmingham & Solihull	33	47	7	5	4	4	470
Black Country (Walsall, Wolverhampton, Sandwell, Dudley)	55	34	2	6	2	1	206
Staffordshire	66	11	0	2	0	21	232
West Mercia (Herefordshire, Shropshire, Worcestershire)	89	6	0	1	2	1	281
All	58	27	3	4	3	5	1313

Diagnosis

Four groups of disorders made up 75% of the population identified. Figure 5 shows a quarter of the children (n=301) had congenital and/or chromosomal disorders. Just under a quarter of children (n=270) had a static encephalopathy, for example severe cerebral palsy. Figure 6 shows a similar profile for children who died in the sample year.

Disease group

- Congenital & chromosomal
- Static encephalopathy
- PIND – CNS progressive
- Cancer
- Pulmonary
- Other
- Neuromuscular
- Prematurity
- Not known/not reported

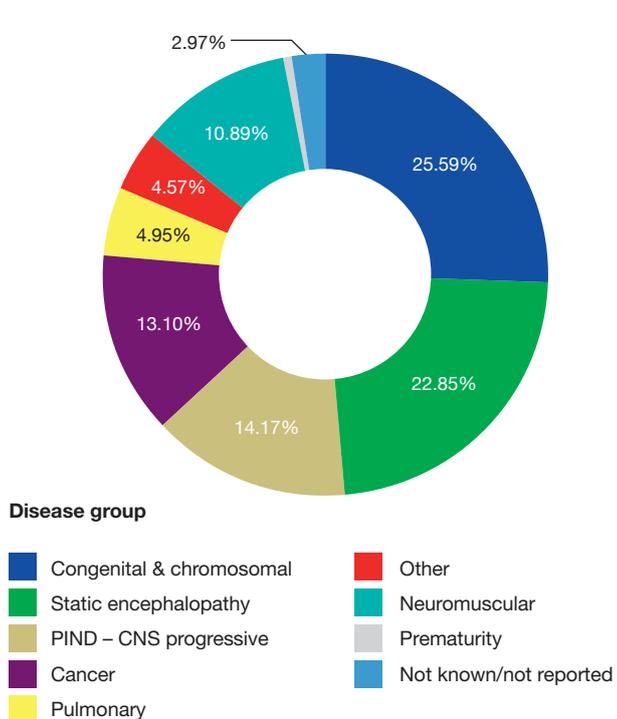*Figure 5: Disease groupings of children (n=1180) with life-limiting conditions known to services at end of April 2011*

Disease group

- Congenital & chromosomal
- Static encephalopathy
- PIND – CNS progressive
- Cancer
- Pulmonary
- Other
- Neuromuscular
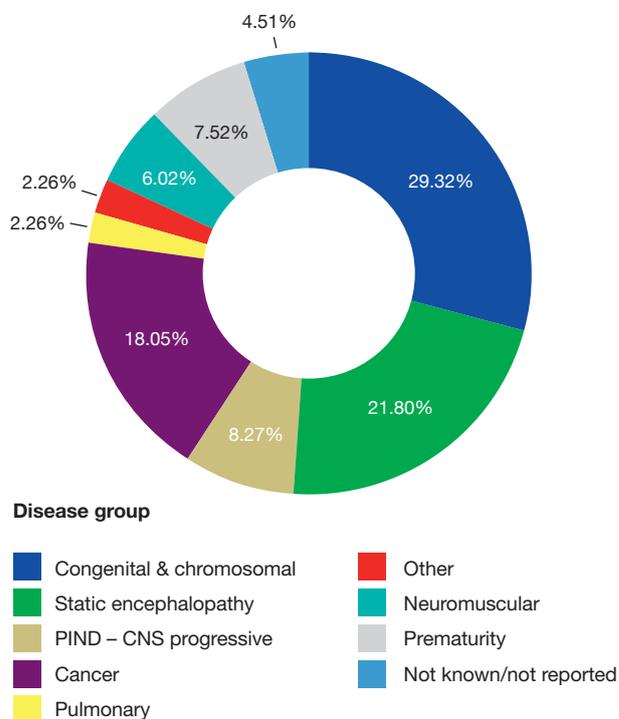- Prematurity
- Not known/not reported

Figure 6: Disease groupings of 131 children who had died 13-24 months previously

Access to children's hospice services
Forty five postcode sectors in the West Midlands were outside a 20 miles radius of a children's hospice service. The hospice in Coventry is age-limited to five years, so provision for older children is limited in that area. Families in Solihull are within a reasonable travelling distance of Birmingham Selly Oak, but this is likely to add to pressure due to high density of children in Birmingham. Another facility to the north of Warwickshire may alleviate pressure on hard pressed hospice services. Elsewhere, 24 families were living further than 20 miles from children's hospice facilities – most of these were living in the Shropshire and Hereford area.

Most families are within 20 miles of a children's hospice. However, in the Birmingham area 433 children were reported (Figure 3) with only one hospice within the area. It seems likely according to these figures that current hospice services could not meet the demand if all these children were to seek support from the service.

1b) Survey Results

The response rate from parents was 12.5% and the response from staff was 52% (Table 4).

Table 4: Distribution and response rates for questionnaires in the Big Study

Questionnaire	Distributed n	Returned n	Response rate %	Free text comments n
Parents	1532	192	12	146
Bereaved parents	180	23	13	17
Staff	504	264	52	211
Service managers	58	21	36	n/a

Demographics

The diagnoses of children described in the questionnaires by parents were categorised as Table 1 (p.12), and are listed in Table 5 below.

Table 5: Disease groupings of children whose parents completed the parent survey

Disease category	n	%
CNS – Static Encephalopathy	46	24
Congenital and Chromosomal	41	21
Neuromuscular	32	17
Cancer	28	15
CNS Progressive	21	11
Other	6	3
Diagnosis not known	2	1
Missing or unable to classify	16	8
Total	**192**	**100**

Children and young people were aged between 0-24 years (median age of 10 years and mean of 9.8 [SD 5.9]). 154 (80.2%) were White British or Irish, 32 (16.7%) were South Asian or British Asian, 3 (1.6) were Black or Black British. Data was missing on 3 (1.6%). Half of all families had no other children in the household. Of the other half, there were up to five other children.

The median household income was between £15,000 and £30,000.

Measure of Processes of Care for Parents (MPOC-56)
The scores for the factors are listed in Table 6. There were no statistically significant differences in factor scores between areas therefore only scores for the whole West Midlands are shown. Lowest scores overall were seen to be given for the factor 'Providing General Information' indicating this is an area where improvement is needed. Highest scores were seen against 'Respectful and supportive care'.

Table 6: Mean score and standard deviation for the five factors of the MPOC-56. Scores range from 1 (Never) to 7 (To a great extent) with 4 at the (Sometimes) point

Factors	Average Scores	Standard deviation
Enabling and partnership (n=174)	5.0	1.3
Providing general information (n=169)	4.2	1.6
Providing specific information about the child (n=169)	5.0	1.3
Co-ordinated and comprehensive care for the child and family (n=172)	4.9	1.4
Respectful and supportive care (n=175)	5.3	1.4

Table 7 below shows the proportion of respondents who scored less than 4 (4 indicates 'Sometimes' experiencing the behaviour in the item) for each factor.

Table 7: MPOC-56. Proportion of families in each PCT cluster area rating services low (less than 4)

Factors	PCT clusters				
	Arden	B'ham & Solihull	Black Country	Staffordshire	West Mercia
	%	%	%	%	%
Enabling and partnership (n=174)	10	23	31	22	31
Providing general information (n=169)	42	38	57	32	61
Providing specific information about the child (n=169)	15	20	24	11	23
Co-ordinated and comprehensive care for the child and family (n=172)	15	25	37	29	35
Respectful and supportive care (n=175)	5	21	26	14	24
Number of parents responding	19-20	46-48	33-35	34-36	33-36

Over 50% of families in the Black Country and in West Mercia rated their services low on 'Providing general information'.

Although there is variation between areas, these differences were not statistically significant. Providing general information appears the least well met need overall. Other studies have also found that families find it difficult to access general information, for instance, about services and financial benefits (Hunt et al., 2003).

Families' met and unmet needs as identified through survey responses
Parents were asked a series of questions about the extent to which the children's and families' needs were met and these are shown in Table 8. Responses to these questions were dichotomised to: 'No need or need is met', and 'Need not sufficiently met' ('we pay for this ourselves', or 'yes, but not enough support').

The four items (in bold at top of Table 8) for which over half the parents indicated poorly met need were in:

• Opportunity to plan future care

• Provision to enable families to have holidays

• Planning for end of life care

• Continuity of care across services

Table 8: Proportion of parents reporting met and unmet needs

Questions	No need or need is met (%)	Need not sufficiently met (%)
Do you have opportunities to plan future care for child?	**21**	**68**
Does your family need special provision for family holidays?	**34**	**63**
Do you have opportunities to plan care for child around time of death?	**24**	**56**
Do you have continuity of care across services?	**40**	**54**
Do you need information about services and how to obtain them?	52	46
Do you need help to be able to take up work as desired?	53	41
Does your child need special play facilities?	58	40
Do you need financial advice and support?	61	36
Does your child's condition need adaptations to your home?	61	36
Do you need help with domestic chores around the house?	63	36
Do you need a key worker to help you organise your child's care services?	62	34
Do you need access to psychological or emotional support for yourselves?	66	33
Do you need help to be able to go out for a short time from home?	65	32
Does your child need help with mobility?	70	29
Relief of other troublesome symptoms?	69	27
Does your child need access to psychological or emotional support?	76	22
Does your child need short breaks away from home (not with family)?	77	22
Do you need information about your child's condition?	78	21
Do your child's brothers and/or sisters need access to psychological or emotional support?	76	21
Does your child receive appropriate education?	80	16
Does your child need relief from pain and discomfort?	81	16
Do family members need spiritual support?	89	10

Care co-ordination

Parents were asked whether they had a named person to contact if they needed help and advice (to find out if they had a care co-ordinator, key worker or similar). Scores ranged from 1 to 7 ('never' to a 'great extent').

The responses were split in to two groups: Low scores (below the median score of 6, needs not met) and high scores (at or above 6, needs met). Differences in MPOC-56 factor scores between low and high scores were examined using Independent-Sample t-tests. Differences were highly significant for all factors (Table 9) indicating that where the families could identify a named person, services were perceived as better.

Responses to a similar question (scores detailed in Table 8), 'Do you need a key worker to help you organise your child's care services?' were also tested. There were highly significant differences between low and high scores (needs not met and met) on each of the MPOC Factors (p=.0001) indicating similarly that where a key person could be identified, services could be perceived as better.

Table 9: MPOC low and high factor scores for the question, 'Do you have a named person to contact if you need help or advice?' (Mean scores: I = 'never', 7 = 'to a great extent)'

Question score	Enabling and partnership		Providing general information		Providing specific information about child		Co-ordinated and comprehensive care		Respectful, supportive care	
	Low	High	Low	High	Low	High	Low	High	Low	High
n	87	98	85	95	84	97	86	96	86	99
Mean score	4.0	5.5	3.3	5.0	4.1	5.8	3.8	5.8	4.2	6.2
Std. Dev	0.9	1.0	1.1	1.5	1.1	1.1	1.0	1.0	1.1	0.9
p	< 0001		< 0001		< 0001		< 0001		< 0001	

Table 10: Proportion of families who rated unmet needs by PCT cluster area

Parents reporting unmet needs	PCT cluster Area					
	Arden	Birmingham & Solihull	Black Country	Staffordshire	West Mercia	Chi Sq P
	%	%	%	%	%	
Do you need help to be able to go out for a short time from home?	9.1	38.6	45.7	27.3	37.8	0.043
Do your child's brothers and/ or sisters need access to psychological or emotional support?	36.4	33.3	15.2	8.9	23.5	0.023
Do you need financial advice and support?	40.9	55.6	41.7	22.2	27.8	0.013
Numbers of families who completed questionnaire	19-22	46-48	33-35	43-46	33-37	

Three items of the 22 examining met and unmet needs differed by area and can be seen in Table 10.

• Whereas the general level of unmet need in going out for a short time from home was quite high in most areas this was only 9% in Arden.

• 36% of families in Arden, however, and 33% in Birmingham needed more psychological support for siblings, while only 9% of Staffordshire families indicated this.

• In Birmingham 56% of families needed more financial advice or support whereas only 22% in Staffordshire did so.

The bereaved parent survey
Four centres chose not to distribute the bereaved parent's questionnaires and there were no replies from seven centres. Twenty three questionnaires were returned from 10 centres. Questionnaires were completed by the deceased child's mother in all but one case. Ethnic origin of children was White British or Irish for 78%, South Asian for 17%. The median age of children when they died was 2.3 years (range 0 to 17 years). Disease categories are listed in Table 11.

Table 11: Disease categories of children who died in the 11 months up to end April 2010

Disease category	n	%
CNS – Static Encephalopathy	6	26.1
Congenital and Chromosomal	6	26.1
Cancer	5	21.7
Perinatal/prematurity	3	13.0
Chronic lung disease	1	4.3
Not known or unable to classify	2	8.7
Total	**23**	**100**

Most families appeared to report a high level of support from medical and nursing staff and good pain and symptom management for their child. Needs were less well met in relation to financial advice and support (52%), and making plans around their child's death (48%). After their child's death nearly half of all parents reported that their need for ongoing psychological, emotional and spiritual support was poorly met (48%).

The staff survey
The staff questionnaire was returned by 264 (52.4% of the total distributed) individuals and showed:

• Half of all staff (49.2%) were over the age of 40

• 90% were White British

• 61% were registered nurses

• 17% were family support or healthcare assistants

• 14% were therapists or social workers

• 3% were doctors

• 46% were educated at degree level or above

• 44% reported that they were a named care co-ordinator (or key-worker) who works across services to help manage a child's care

Measure of Processes of Care for Service Providers (MPOC-SP)
From the 264 returns, 260 individuals had completed the MPOC-SP. Practice is rated on four factors:

• Treating people respectfully (TPR)

• Showing interpersonal sensitivity (SIS)

• Communicating specific information about the child (CSI)

• Providing general information (PGI)

The items are scored on a scale of 1-7 ('never' to 'a great extent').

No significant differences in the MPOC-SP factor scores were found between PCT cluster areas.

Table 12: Descriptive statistics for the four MPOC-SP domains (n=260 practitioners)

	Mean	Std. Dev	Min	Max	Percent scoring < 4
Treating people respectfully (TPR)	6.1	0.6	4.1	7.0	0.4
Showing interpersonal sensitivity (SIS)	5.4	0.9	2.9	7.0	8
Providing general information (PGI)	4.3	1.5	1.0	7.0	40
Communicating specific information (CSI)	4.1	1.9	1.0	7.0	41

Table 13: Differences in the MPOC ratings of members of staff who described themselves as a care co-ordinator or not a care co-ordinator

MPOC-SP Factors	Care co-ordination role	n	Mean (SD)	p=
Showing interpersonal sensitivity (SIS)	Not care co-ordinator	148	5.0 (1.0)	< 0.001
	Care co-ordinator	116	5.8 (0.8)	
Treating people respectfully (TPR)	Not care co-ordinator	148	6.0 (0.7)	0.012
	Care co-ordinator	116	6.2 (0.6)	
Communicating specific information (CSI)	Not care coordinator	148	3.6 (1.9)	< 0.001
	Care co-ordinator	116	4.8 (1.7)	
Providing general information (PGI)	Not care co-ordinator	148	3.9 (1.6)	< 0.001
	Care co-ordinator	116	4.7 (1.4)	

The mean scores for the four domains introduced above are shown in Table 12 above. Staff scored items 'Providing either general information' (PGI) or 'Information specific to the child' (CSI) considerably lower than 'Treating people respectfully' and 'Showing interpersonal sensitivity' (TPR and SIS), indicating they give lower priority to meeting needs for information than 'being nice'.

Several healthcare assistants (HCA) and family support workers (FSW) also indicated 'not applicable' (to their role) when scoring items within the PGI and CSI factors (communicating and providing information) and thus this group scored lower than other roles. Although not ideal, given the families' needs for information (Table 6), this is commonly the case in other studies (Dyke et al., 2006; Jeglinsky, Autti-Ramo, & Brogren Carlberg, 2012; Whitton et al., 2008). Staff may underestimate families' needs for both general and specific information.

Staff who reported being a care co-ordinator or key worker (including those who were FSWs and HCAs) scored significantly higher than those who were not for each factor (Table 13). This finding indicates significant value being placed upon this role in practice.

Staff perceptions of children's and families met and unmet needs.

Table 14 shows the proportion of staff who rated the needs of families as poorly met (scored 1-3 from a range of 1 (Not at all) to 7 (More than needed)).

Whilst the staff agreed with parents (parent survey) that pain and symptoms are well managed, staff have tended to perceive items relating to planning for the future and provision of information as better met than parents. They also recognise that the social needs of families are not well met.

Table 14: Proportion of staff who rated the needs of families as poorly met (scoring 1-3 from a range of 1 (Not at all) to 7 (More than needed))

Staff survey	ALL %
Domestic help with chores around the house	86.6
Parents able to work as desired/as appropriate – part time	82.5
Parents able to work as desired/as appropriate – full time	74.5
Access to short breaks at home	57.9
Spiritual support for family members	57.2
Necessary adaptations to house	52.2
Access to short breaks away from home with family/holidays	48.0
Access to short breaks for child away from home (not with family)	44.8
Access to psychological/emotional support for siblings of affected child	44.7
Access to psychological/emotional support for affected child	42.3
Opportunity to plan future care for child e.g. transition to adult services	40.7
Financial advice and support	39.0
Access to appropriate play facilities	38.6
Access to psychological/emotional support for parents	37.4
Continuity of care across services	33.2
Help with mobility e.g. buggy, wheelchair, adapted car	32.8
Key worker to help organise the child's care services	29.2
Access to appropriate education for affected child	28.2
Access to bereavement support	23.4
Opportunity to plan care for child around time of death	18.7
Information about services and how to obtain them	15.1
Information about the child's condition	13.4
Relief of other troublesome symptoms	8.4
Relief of pain and discomfort	6.4
n of staff	239-255

Table 15: Geographic area differences in seven items scored by staff on the MPOC

	ALL %	Arden %	B'ham & Solihull %	Black Country %	Staffordshire %	West Mercia %	Chi square p
Access to short breaks at home	60	36	**74**	57	57	57	0.004
Spiritual support for family	57	61	44	66	**83**	57	0.011
Necessary adaptations to house	52	41	59	**70**	65	42	0.015
Short breaks away from home	48	42	**65**	48	46	37	0.013
Opportunity to plan care for child	41	37	**54**	20	**54**	35	0.008
Financial advice and support	39	41	34	47	**71**	30	0.005
Access to appropriate play facilities	39	20	**54**	**57**	22	34	<0.001
n	239-255	42-46	64-69	27-30	21-24	81-86	

Differences between PCT cluster areas

The staff questionnaire was analysed by the geographic PCT cluster area. There were seven items of perceived need from 24 that showed highly significant differences between geographic areas (Table 15). Higher proportions are highlighted in bold.

Compared with the other cluster areas:
- A larger proportion of staff from Birmingham and Solihull perceived the following needs of families as being poorly met:
  - Access to short breaks
  - Planning for future care
  - Access to play facilities

- Staff from Staffordshire perceived the following needs of families as being poorly met as compared to other areas:
  - Spiritual care
  - Planning future care
  - Financial support

However, staff did feel access to play facilities was well met.

- Staff from the Black Country perceived the following needs of families as being poorly met, or unmet, as compared to other areas:
  - Adaptations to houses
  - Play facilities

However, staff did feel that planning future care needs were well met. This may reflect particular emphasis on this aspect of care by their senior clinicians.

- Arden and West Mercia staff were generally more positive that family needs were being met.

The service manager questionnaire
Nineteen services out of 21 responded to the service manager's questionnaire.

A variety of services were provided, including short breaks at night and during the day, counselling and emotional support, end of life care, parent support groups, befriending services and bereavement services including sibling groups.

All the hospices and some NHS services were providing 24 hour care 7 days a week. Other NHS services offered 24 hour telephone contact and end of life care 'as required', usually on an ad hoc basis and dependent on the good will of staff who might not be able to reclaim this time.

Service managers identified 105 whole time equivalent (WTE) registered nursing staff employed by hospices, whereas 50 WTE registered nursing staff were recorded as NHS employed. Only one hospice reported that they had vacancies that were hard to fill. These were primarily children's nursing posts, but four NHS services reported unfilled vacancies in children's nursing posts, and one social work post.

Limitations of the current services
Hospice managers reported anecdotally in their comments, few referrals of Afro-Caribbean, Jewish, or travelling families. In addition, there were few referrals of neonates for hospice care and limited provision for home care. Involvement with children with neoplastic disease tended to come at a very late stage in the child's illness.

NHS service managers indicated in their comments, poorly met need for families in: children who had complex care and social support needs; those experiencing financial difficulties; and families from Black and Minority Ethnic communities. They also reported poor provision for families requiring psychological support where the child did not have a nursing need, for example where a child has been recently diagnosed, the child and family may require emotional support.

Responses to open ended questions across all surveys

Parents and staff were asked to respond to the question, 'What three things would you change about the services or the help you have had that would make the biggest difference to the quality of your family life or to other families?' In total, 476 questionnaires were returned from parents and staff and 374 of these contained comments (146 from parents, 17 from bereaved parents and 211 from staff).

Open text responses were organised into four areas of change illustrated by typical comments.

- Better communication and co-ordination (32 parents, 6 bereaved parents, and 51 staff)

> *If we had a co-ordinated, integrated care package that was planned around our child and followed wherever our child went, with a shared team that know our child well, then I wouldn't have to continually manage peaks and troughs of crisis. The system does not support us at present I am dragged into bureaucracy and administration and I feel a sense of hopelessness that I am not able to provide for any of my children properly. I just want to be mum and wife to my family, not super woman.*
>
> **(Parent)**

- More financial support (59 parents, 4 bereaved parents)

> *My partner and I both had to give up full time employment to care for our child. After our child passed away I was able to find employment but my partner has only just been able to gain employment three years later. During this time no financial support has been available and some would have been welcome in this stressful time.*
>
> **(Bereaved Parent)**

- More social and emotional support (13 parents, 5 bereaved parents and 51 staff)

> *We are very fortunate in our area to have a very supportive consultant who makes herself available 24 hours a day during end of life care that allows families and ourselves access to advice and reassurance at critical times to give the children and their families the best possible death. This has enabled a lot of the families to cope with the tragic loss of their child and reflect positively when life must feel so negative. It would be nice to think this is the case in all areas of the country.*
>
> **(Staff member)**

> *…For medical staff to stay in touch after child passes away. They were part of our family for three and half years…losing a child is the worst thing anyone can experience so protecting the family afterwards is paramount to helping them still be members of society, but there is no support out there for families.*
>
> **(Bereaved Parent)**

- More respite care (14 parents and 39 staff)

> *Everything was a constant battle.Even got refused a disabled badge at first. Had to fight to get respite and only got it the last six months of his life.*
>
> **(Bereaved Parent)**

Limitations

Services were only able to provide the MDS for families who had been given the opportunity to opt out, but decided not to. The MDS was designed to minimise loss of information in anticipation of low response rate from questionnaires and to minimise parent burden. It represents the number of children known to and reported by services. Two services invited decided not to participate and a third did not circulate the parent questionnaire. Some managers within services that did respond were protective of their patient group and decided not to invite families where the child was having active treatment or where they were unsure of the families' understanding of their child's condition. Therefore, the size of the population is dependent on the professional's interpretation of individual circumstances as well as their interpretation of which children have conditions that are life-limiting or life-threatening. It is well recognised that there is uncertainty in this area. Our figures are therefore likely to be a conservative estimate of true prevalence.

Summary

Approximately half of all children were diagnosed with a static encephalopathy or a congenital/chromosomal condition. The median age of children was approximately 8 years and 3.5 for those who had died the previous year. 37% were from ethnic minority backgrounds. Approximately 12.5% of parents invited to complete the questionnaire responded. Both staff and parents indicated that communication of information was less well provided than that of respectful and supportive care. Professionals may underestimate this need. Having or being a named person or care co-ordinator impacted positively across all domains. There seemed to be a higher level of unmet needs for families in the densely populated areas of Birmingham and Solihull. Half of all parents indicated poorly met need in opportunity to plan future care, planning for care around the time of death, opportunities for family holidays and continuity of care across services. Staff did not rate the parental need for planning for the future and the provision of information as highly as parents, but recognised the need for more social support for families.

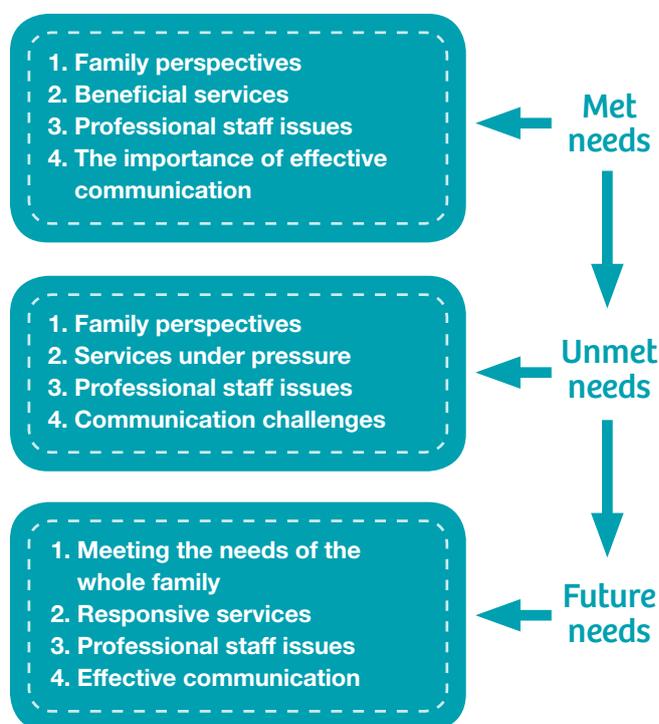# Strand 2: Understanding the met and unmet needs of children and families

Demographics of interviewees

Participant breakdown of the qualitative analysis is shown in Table 16 below. Sixty-six families were approached and of them, 51 participated in the study which included 59 individuals (41 adult parent/carers and 18 children and young people aged 5-18).

Of the qualitative sample, 74% of adult participants were mothers and 13% were fathers. Adult participants also included birth grandparents, foster grandparents and adoptive parents who play a primary care role for the child or young person. Although only 18 children and young people were interviewed, within the 51 families, there were 53 children and young people with life-threatening or life-limiting conditions, of which 55% were male. A variety of children and young people's conditions were evidenced: 21% are in the static encephalopathy and congenital and chromosomal group whilst 19% have conditions within the neuromuscular group. Of the total sample, 36% of participants were in the 5-10 age banding and 15% were in the 11-15 age banding.

Using Framework Approach analysis, a reporting framework was developed of met and unmet needs (Figure 7).

Figure 7: Report framework

1. Family perspectives
2. Beneficial services
3. Professional staff issues
4. The importance of effective communication

Met needs

1. Family perspectives
2. Services under pressure
3. Professional staff issues
4. Communication challenges

Unmet needs

1. Meeting the needs of the whole family
2. Responsive services
3. Professional staff issues
4. Effective communication

Future needs

(Explored further on p.58-61)

Table 16: Number of families and participants interviewed

	Families recruited	Potential total family members	Families interviewed	Individuals interviewed
Adult data set **(Parent/s and family carers)**	66	147	39	41 parent(s)/family carers
Children and young people data set (Age 5 years to 18 years)	No child recruited without family consent	33 No child invited without family consent	12	18 children and young people (6 parents present with children but who were not interviewed)
Total	**66 potential families**	**180 potential participants**	**51 families**	**59 participants**

Met Needs

Family Perspectives

The interviews showed that families were living as normal lives as possible, albeit in abnormal circumstances – with many parents and carers, such as grandparents and adult siblings, educating themselves with all they needed to know to help them deal with what was happening. Maintaining a positive outlook was cited as an important strategy for coping across all families and was commonly discussed:

> *There is a really positive side. [My child] is a very happy child. Curiosity is her major thing!*
>
> **(Family day interview 1, Father, Arden)**

Seeing the situation as part of their life helps some parents to cope whilst some families find their faith or cultural way of life supports them:

> *I am the sole carer for my son. I gave up my job nine years ago to look after [my child] and my husband stopped work a year ago to help me.*
>
> **(Participant 37, Mother, Arden)**

> *We should count our blessings. We have got a boy and although we were told he only had four hours to live he has grown to be seven years old and that is a blessing in disguise. I can't complain. I am very fortunate – I have got a lovely family that supports me and helps me – a very nice wife …there is no reason for me to complain.*
>
> **(Participant 45, Father, Birmingham)**

Beneficial services

Having trust and confidence in a service delivering holistic care to their child was very important to families. Parents and carers felt their child had the right to expect care to be provided at home and that hospital admission should be prevented or reduced to a minimum. A number of families said that having a lead discharge nurse in the hospital or hospice and/or a Community Children's Nurse or team available had enabled their child to be discharged 'earlier'.

Overall, in the West Midlands, families were supported by a wide range of professionals such as physiotherapists, speech and language therapists, play therapists, family key workers, sibling workers, teachers, teaching assistants, social workers and health visitors. All the participants felt that the personal and professional attributes of staff were important. This impacted on their views of the service and the two were often reliant upon each other. Health and education teams in many cases had provided personal support to parents who were experiencing enormous stress. Children and young people felt that professional and

family carers who were of a similar age to themselves were particularly able to relate well to them and they were able to discuss common interests.

Accessibility of support was highlighted as important, as was being able to make contact and to receive support out of normal working hours. Community staff from Arden and West Mercia NHS clusters were praised for their expertise and ability to match support to individual family needs:

> *…it's having continuous contact with someone that's there, that understands what you're going through…*
>
> **(Participant 20, Mother, Arden)**

> *…to know that I can just phone up and have somebody to talk to who knows all about us and [my child], today, anytime, 24 hours a day is wonderful… now that she knows everyone and she's built up a good relationship with the team in [a hospital]…I just can't fault it…*
>
> **(Participant 53, Mother, West Mercia)**

> *…Our key worker at special school is like a friend. She gives me one to one emotional support. She is the first person I would contact if there was a problem and she would get the right help for me. My son gets lots of support from there.*
>
> **(Participant 37, Mother, Arden)**

Care packages were frequently discussed among parents and carers. Community Children's Nurses (CCN) teams were felt to provide a high standard of service. Care packages mainly involved complex or continuing care, with end of life and palliative care frequently being cited as vital aspects of support with high quality palliative and end of life care needed 24/7, based around the family's needs. Despite limited resources in some cases, parents and carers felt that teams, especially medical and nursing, accommodated choice and implemented a number of local initiatives to support the whole family.

Respite and short break care services were frequently reported as beneficial, as assistance with day to day care eases the pressure on parents/carers and makes a positive change to their daily lives. If family circumstances change this appears to put family members under enormous strain. Consequently, when families are able to access routine respite, emergency respite or short break care, it gives them opportunities to take time away from caring duties.

> *…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)**

Respite is arranged through different services across West Midlands Children's Services, for example, through community respite services, hospices and voluntary organisations. Overall, parents and carers in all NHS clusters had confidence that the service was there when needed and they valued this continued support. Where service providers are able to respond quickly when a family needs support, this was highly praised:

> *Any time you need them they come out especially if she's ill they come straight out and if they can't then they advise you what to do to bring her to the hospital and stuff.*
>
> **(Participant 31, Mother, Birmingham)**

Children's hospice services were perceived as very beneficial to the family members who had used them. Staff were described as knowledgeable, skilled and compassionate to family needs. The choice of facilities available and social opportunities were recognised and highly valued:

> *I went on a trip once and it was great so that was nice.*
>
> **(Participant 42, Child, Girl, Arden)**

Provision of care in special schools and mainstream settings was reported to be important in meeting individual needs. In the latter, inclusion of the child or young person into the setting was varied. Support for transition between phases of education is also varied, but generally parents feel that they are included in decisions about their child. Services that are provided locally to family homes through the child's school (e.g. physiotherapy) and tailored to individual needs are very useful for families. Many families reported school staff had gone beyond the call of duty and they appreciated this. Special schools in some areas were highlighted as providing particularly good holistic educational care:

> *Most of those things are 'actioned' through the education system because she's in a special school... there's on site physio, on site occupational therapy and visual impairment stuff done through there as well...all her aids are done through school as well.*
>
> **(Participant 21, Mother, Arden)**

> *And ….my nurse told my teachers (about my condition) and they all know and look out for me.*
>
> **(Participant 6, Child, Boy, Arden)**

Three adult participants from across the West Midlands NHS clusters discussed that they received a Direct Payment to tailor care plans to their needs, which worked well for them. One carer said this allowed a family member to be employed to provide care which allows the parents to have some time out.

Professional staff issues

Participants valued professional multi-disciplinary staff (health, education and social care professionals) who are confident, positive in attitude, competent, knowledgeable, dedicated, flexible, accessible, friendly and approachable. Continuity and consistency of staff was important and firmly linked with familiarity, support and trust. In particular, Community Children's Nurses were highly rated in terms of providing children and young people with excellent care. Additionally they provide opportunities for children to take part in activities with their families and peers, which is highly valued. There were positive examples of staff responding to the individual needs of children, young people and families within all the NHS clusters and in some instances services had been able to adapt protocols to incorporate holistic care:

> *Children's Community Nursing is really astonishing care, offering a collection of tools, like two hourly slots each week, general activities to help with [my child] swimming, Guides and dancing sessions and hospital team to check on wounds and dressings.*
>
> **(Participant 33, Mother, Staffordshire)**

> *...the [service delivering milk/medicine]...they're wonderful to us...the good thing about it, not a year ago I managed to push for us to go on holiday...and they sent me a whole box out...a whole medical box... [service delivering milk/medicine] sorted it all out...*
>
> **(Participant 25, Father, Black Country)**

> *She's got a good consultant looking after her and she's got the same carers and nurse coming in week after week so they're building a nice relationship...*
>
> **(Participant 2, Mother, Black Country)**

Continuity and consistency of staff was also highlighted by many children, as a crucial element of maintaining trust and confidence and allowing levels of familiarity to develop. Many of the children and young people referred to how well they knew their carers and the relationship having developed over an extended time period, and in some cases the child's whole life.

> *They know what they are doing and I feel safe and they talk about TV shows and what we did at the weekend.*
>
> **(Participant 41, Child, Girl Arden)**

> *It's important having someone who knows us.*
>
> **(Participant 62, Child, Boy, Arden)**

In addition to regular service provision, participants across West Midlands NHS Clusters identified a number of additional services which they found to be beneficial such as transport, specialised beds and leisure and play time activities. Services also included additional health services such as physiotherapy and speech and language therapy as well as complementary therapies for both the child and parent. Parents/carers directly named professionals who they felt had 'gone the extra mile' in providing personalised care for their child:

> *He gets physio once a week. A play therapist comes during term time. Then we get speech and language therapy and a dietician as well.*
>
> **(Family day interviews 2, Father, Arden)**

The importance of effective communication

In order for families to adjust to their child's needs and to develop coping strategies, all family members need accurate and up to date information. Some families feel that it is important to talk to their child about the condition and to involve them in decisions that are made.

> *I never hide anything from [my child]. I always find a way of telling him. I might make a story out of it or something – I never hide anything – he can't talk but he can hear everything.*
>
> **(Participant 37, Mother, Arden)**

Services were better able to meet family needs where there was good communication. This included verbal and written communication as well as discussions during organised meetings. Some parents and carers highlighted professionals or services by name who had been particularly good in communicating with them. Being listened to, consulted and included in the 'care team' was also important for parents/carers.

Participants felt that the health professionals could provide a much needed and trustworthy line of two-way communication, between themselves and other healthcare professionals. Front line health professionals such as qualified Community Children's Nurses often acted as advocates to the parents, for example offering to be present when other professionals such as doctors were informing them of changes to their care packages. Family members felt that this improved communication and established better levels of consistency and continuity of care across and within services of the West Midlands. The quote below from a young girl highlights this:

> *...Everybody knows if there's a change in [something].*
>
> **(Participant 66, Child, Girl, Arden)**

Children and young people endorsed a need to voice their views and to be involved in decisions regarding their care. Having someone outside their family to whom they can talk provides a much needed 'safety valve' when children and young people are confused or frightened and they do not want to talk to their parents.

> *Yeah, yeah, I get a say in what happens [in terms of care received]*
>
> **(Participant 8.2, Child, Boy, West Mercia)**

> *She talks to me on my own sometimes … yeah I like that.*
>
> **(Participant 41 Child, Girl, Arden)**

> *…we get involved not just our parents.*
>
> **(Participant 11.2 Child, Boy, Birmingham)**

Some brothers and sisters spoke about their fears for their sibling. Where there are opportunities to meet other siblings in similar circumstances, this is viewed as beneficial, providing that families are able to access the support without making further demands on them.

Parents and carers spoke of being able to approach service staff with seemingly small things that cause them anxiety. Some appreciated that health professionals treat the child or young person as an individual and communicate in a sensitive, thought out way with language tailored to them:

> *...we've now got a paediatrician that actually listens to us; we've found a GP that listens to us...*
> **(Participant 24, Father, Staffordshire)**

The ways in which information regarding diagnosis, prognosis and treatment is communicated is praised by some parents/carers. In particular the interpersonal skills of the messenger is important, taking time to answer any questions as well as the inclusive approach of sharing information with the affected child and family members such as:

> *I was told the news on the Friday and my whole world fell apart. It was awful as you can imagine. It was all done in a lovely way and the consultant told [the child] but [they] didn't use the word cancer.*
> **(Participant 57, Mother, West Mercia)**

Collaborative partnerships between professionals and families worked well with school nurses, paediatric and community consultants, community nurses and special schools. Participants were generally well informed and cited positive examples of how health, education and social care delivery had been jointly planned and delivered in partnership with the users. What worked particularly well was the inter-team working and sharing of resources through the Common Assessment Framework (CAF).

> *The best thing is when all the doctors and nurses communicate with one another. In all departments they work towards the same goal. And they feed back to me about…[my son].*
> **(Participant 37, Mother, Arden)**

Social networking was cited as a way of making contact with parents in similar circumstances.

> *I've actually found an awful lot of emotional support from the internet [social network website]...managed to meet up virtually as you say with a lot of people who have similar difficulties... brilliant source of support.*
> **(Participant 32, Mother, Birmingham)**

Unmet Needs

Family perspectives

Many family members described the exhausting level of care they undertook and some expressed their anger and frustration towards the substantial stress of caring for their child. Although no parent said that they would want this differently, some described their home as more like a hospital or clinical setting than a family home. The complex psychological support needs of family members were often thought to be left unmet, because they felt that the focus was on medical treatment or care of the affected child or young person. Family privacy was often compromised by the number of carers and health professionals visiting the home. This had an impact on the time available to participate in social activities and relationships often became strained between family members:

> *Me and my husband, we can't just go out of the house and leave [our son] and de-stress.*
> **(Participant 37, Mother, Arden)**

> *Our home …it's just a public building. I said that to my husband – we both feel like that.*
> **(Participant 9, Mother, West Mercia)**

When normal routines were interrupted, it puts families under enormous strain and in some cases results in parental guilt about how to spend equal amounts of time with all their children:

> *I feel that I have let my other children down because all I ever did was for [my child] I didn't neglect the other two but I didn't give them any of my time.*
> **(Participant 59, Mother, Birmingham)**

Services under pressure

There were reported situations where parents had lost faith in the quality of service provision. In some cases they felt that this had jeopardised their child's survival and recovery after an acute episode of bad health.

It was also reported that children and young people had frequent experience of an acute medical crisis and had to be admitted to hospital as an emergency. There would appear to be few systems in place which enable a child's case history to be retrieved immediately on their admission to hospital. Parents were frustrated by the amount of time needed to give information about their child. Issues discussed included a need for rapid mobile and bleep systems and improved use of information technology across services so that they do not have to waste precious time telling their story.

> *When our care was transferred to [the local hospital] the doctors and nurses did not communicate with each other. Every time we have to go to A&E or he has to be admitted there is a new doctor each time and I have to give a complete story from when he was born. Why isn't the information already there on the computer? Why haven't they got his notes?*
>
> **(Participant 37, Mother, Arden)**

A further issue of frustration related to inconsistency of professional working patterns across the West Midlands region, not only of health and social care staff, but also of education providers. A number of parents talked about healthcare only being delivered five days a week and between 'standard' working hours whilst other parents had 24 hour care. In some cases participants voiced frustration because they perceived that a postcode lottery determines whether they are able to access support or not. Some families reported having to travel considerable distances to access specialist services:

> *We have to go to [a hospital] for the first course of each IV treatment. It needs to be done in hospital in case there is a reaction. Why can't it be done at (the local hospital)? It is just six miles down the road, instead of 20 miles. People can choose where they have their operations so I don't see why I can't choose where [my daughter] has her treatment.*
>
> **(Participant 35, Mother, Arden)**

There was a strong sense of there being inequity in provision of equipment which means that some families have to fight for their rights, with disparity being present across the West Midlands region:

> *We have to fight for everything – from wheelchairs to adaptations around the home. It puts a huge strain on your marriage because one or other of you nearly always has to fight for something.*
>
> **(Participant 3, Mother, Birmingham)**

Some parents and carers felt that they were particularly challenged by limited availability of supplies. There were occasions when parents commented that the expiry dates on prescribed feeds were too short whilst others reported that equipment was not age appropriate. Many parents and family carers felt that all families, wherever they lived, should be entitled to 'the same' service. Some suggested that unmet needs were 'getting worse' especially specialist physiotherapy and occupational therapy:

> *...I'm asking for a physio, physio, physio but nobody knows...every time I try and phone them and ask I never get a straight answer...the only thing I want and really need is just the physio, I would scrap all the treatments at the hospital because we only go there to talk. I mean I travel 45 minutes to the hospital...they talk to me for 20 minutes and send me back home...all I want them to do is get a physio.*
>
> **(Participant 12, Mother, Birmingham)**

Children and young people were also very aware of the current financial constraints. They suggested expenditure should be focused on increasing healthcare services and greater availability of mobility equipment such as wheelchairs. Some of the older young people had responsibility for deciding how they would spend the Direct Payments allocated to them and this gave them a vital sense of responsibility. If financial support was withdrawn, this often compromised the quality of the young person's life and that of their family.

> *Not good really now that they're stopping the money and everything so less services are going to be given out.*
>
> **(Participant 11.2 Child, Boy, Birmingham)**

> *...the most important thing to spend it on would be healthcare and wheelchairs and stuff like that, that's all.*
>
> **(Participant 8.2 Child, Boy, West Mercia)**

The two areas of service delivery that created the greatest challenges were short break care and end of life care. Across all the regions of the West Midlands Children's Services, families felt that both end of life care and respite care created an enormous challenge for many of the health services to respond to. These services are highly valued by families and demand for them was high:

> *There isn't any opportunity for me to have respite where I still feel like I'm in control with the kids. There's not many activities that happen in the short breaks as well for younger children, more for five and over. It's very difficult to access things for three year olds.*
>
> **(Participant 52, Mother, Arden)**

> *Interestingly, when we lived in [one place], the respite home that she uses wasn't suitable ...but as soon as we moved to [another place] it was more suitable.*
>
> **(Participant 21, Mother, Arden)**

Parents and carers were frustrated when they had to make repeated requests about their child's care and feel they have expended a great deal of time and energy chasing up professionals with their unmet needs or endeavouring to sort out mistakes which could potentially have compromised the care their child received:

> *The chemists kept getting it all wrong all mixed up… [Carer comes in] we've had lots of issues where the wrong medicine, the wrong dosage…I've had to keep going back and going, 'you've not put the right label on…'*
>
> **(Participant 26, Carer, Staffordshire)**

> *…I had fights with the GP receptionists on the phone to get the GP to come to the house because they refused and told me to call an ambulance instead. But eventually I got that sorted and they came to the house...*
>
> **(Participant 32, Mother, Birmingham)**

Although inclusion of children with special needs into mainstream education is enshrined in UK law, holistic provision in mainstream settings is often poor. Many children and young people encountered difficulties with regard to learning and listening, reading and concentration, memory and organisation. It was also harder to maintain continuity of learning in mainstream schools if the child had frequent appointments which took them away from the school environment.

> *…the nurseries just wouldn't take her on...the only one we found which was five miles away from home, we had to travel and it's costing us a fortune to pay for it – because we're both in full time work we couldn't get any discount or nothing...*
>
> **(Participant 25, Father, Black Country)**

> *We wanna keep him at school he only does half days now…but he's like the only one in a wheelchair there like all the time…it does affect [the child] a lot because he does want to be the same as the other children.*
>
> **(Participant 26, Mother and Carer, Staffordshire)**

Educational transition was also stressful:

> *…we found out about 14 weeks before he was due to leave his education environment... he has been in transition since he was fourteen why does it take until almost the very last minute for our security and peace of mind...but we have got that now...but it was a very hard and stressful time getting there...*
>
> **(Participant 19, Mother, West Mercia)**

Professional staff issues

Clearly, staffing and funding limited the capacity of health, education and social care teams to respond to some families needs. This was most notable in having appropriately trained and experienced staff to provide care at home. Some family carers described situations where trained staff were sick and therefore not able to cover a full shift. When a replacement was unavailable, parents and carers reported that they had to take over responsibility for care which added to their stress. Similarly, some families also reported that when their child was admitted to hospital and a ward was understaffed, they were asked (or expected) to care for their child. Some parents talked about being more highly skilled and trained than carers, both in the home and hospital settings, and this did not inspire their confidence. Less experienced staff were often doubted by families in terms of having the skills and knowledge in the care of children and young people with life-threatening and life-limiting conditions. One participant sums this up:

> *I think a lot of the agencies, when we ask them for carers, they don't send people that are trained in having the kind of experience I think that causes a lot of problems….I don't mind training and they listen...*
>
> **(Participant 11.1, Mother, Birmingham)**

Despite parents' wealth of experience regarding practical care (including complex medical procedures), there were numerous reports that hospital nurses and consultants addressed parents in either patronising ways or, conversely, they spoke in medical jargon which was difficult for parents to understand. Also on a number of occasions, it was reported that consultants only talked to the mother of the affected child despite both parents being present. On two occasions it was reported that a hospital doctor failed to give the parent any explanation about the child's illness and just handed the mother a leaflet;

> *[Doctors] will be standing there talking about your son and I think, please explain it to me. And they get quite offended when I challenge them. I think, tell me what is going on. (Participant 59, Mother, Birmingham)*
>
> *Whenever we get asked, it's always my mum gets asked …they won't ask us.*
>
> **(Participant 11.2 Child, Boy and 11.3 Child, Boy, Birmingham)**

Staffing and funding limited the capacity of health and social care teams to respond to a family's choice for their child's end of life care to be provided in their own home. Equally, there were problems in having appropriately trained and experienced nurses to provide the care.

Communication challenges

Parents and carers rely on good communication between themselves and professionals, and across different services. However, there were many instances cited when communication had broken down and when professionals'

interpersonal skills were felt to be lacking. Communication appeared to be worse in hospital settings, with only one cited breakdown in one of the children's hospices. Parent and carer experiences were also varied regarding communication shortfalls across the region. Parents and carers expressed low satisfaction due to a lack of communication between services and relaying important information to families. Parents and carers were confused and frustrated by the situation which they perceive as unfair.

> *It is a minefield finding out what you are entitled to. Most of the things we have found out by accident. There are all those services out there but they should make it more transparent – a directory or something.*
>
> **(Family day 1, Father, Arden)**

> *…I mean the care is out there for you, you just have to find out. If somebody sat me down and told me all this someday, nobody told me we had to find out ourselves...*
>
> **(Participant 25, Father, Black Country)**

Understandably parental anxiety was high, particularly at the time of their child's diagnosis. The way in which parents received the news varied between face-to-face meetings and through telephone conversations. There was one instance when a mother heard the news through a third person. On several occasions a consultant had broken the news in a matter of fact way and then walked out of the room leaving the parent to cope alone:

> *Then the paediatrician phoned one evening when my husband was out and said [the child] has got spinal muscular atrophy, if you want to look it up on the internet you can find out all about it. I remember thinking it was quite callous. It was shocking – I had six weeks off work. ...you either go up or go down and I am not going to let [the child] have a miserable life.*
>
> **(Participant 4, Mother, Gloucestershire)**

> *The way we were given the diagnosis wasn't the best – it was in a normal clinic appointment. The doctor was looking at his watch at one point. I asked what sort of research was going on [to help] and the doctor said, don't worry about that, just love him.*
>
> **(Participant 14, Mother, Gloucestershire)**

Across the region, the availability of information was very varied and easily accessible information was the exception rather than the rule. A large number of families said that they would like more opportunities which enabled them to communicate with other families who were in similar circumstances. This included online communication such

as social networking. Some parents would welcome an opportunity to attend voluntary support groups where they could meet other parents and carers with a child or young person diagnosed with a life-threatening or life-limiting condition. There appears to be a lack of centralised information about voluntary services and support groups which is easily accessible to families.

Collaboration and communication between services was often fragmented and unsatisfactory, which necessitates families having to be proactive in contacting services and updating them with information and often having to repeat their story over and over again to a number of different professionals. This was across many of the clusters studied but interestingly was most evident in areas where there was provision of wide ranging multi-professional services.

> *It is like banging your head against a brick wall. None of the doctors [across the region] speak to each other – they all do their own thing and that's it.*
>
> **(Participant 37, Mother, Arden)**

Parents and carers mentioned occasions when different professionals gave them conflicting advice and this was particularly disconcerting when parents were learning new complex medical procedures or when parents had to hand over the administering of medicines to their child. There also appeared to be a problem in relation to the information or advice given to parents and carers regarding how to use equipment that a child or young person requires.

Summary

Using Appreciative Inquiry and Framework Approach analysis, the qualitative arts-based, in-depth interviews highlighted a number of met and unmet needs from the perspective of 59 participants, including children and young people with life-threatening and life-limiting conditions and their families across the West Midlands. Seeking the views of children and young people with life-threatening and life-limiting conditions and their families will challenge practice and will have economic resource implications. As young people survive longer the demand on services will increase and consideration will need to be given to a multi-dimensional, joined up and seamless approach across health, social care and education services.

The research has highlighted the importance of taking into account what children, young people and families need so that informed service improvements can be made. Consequently, any future planning for service delivery should be undertaken in partnership with children and young people with life-threatening and life-limiting conditions and their families.

Strand 3: Understanding how professional networks support services

Background to the West Midlands Paediatric Palliative Care Network

This part of the study provides a social network analysis of the West Midlands Paediatric Palliative Care Network (WMPPCN). The Network began as an interest group which started in the year 2000 with six to 10 members and grew. At one stage it was allied to the Birmingham Cancer Network and funded by the NHS Strategic Health Authority and at this stage it became more representative of services and West Midlands geography. The membership is wide and inclusive and 30 to 40 people (approximately half the total membership) may attend bi-monthly meetings. Subgroups manage work in specific areas, e.g. transition or clinical standards. There are links to other related networks with reciprocal membership and informal links to NHS commissioners. The geographical area of the network includes Birmingham, Coventry, The Black Country, Herefordshire, Shropshire, Solihull, Staffordshire, Stoke-on-Trent, Telford and Wrekin, Warwickshire and Worcestershire.

Aims of the network analysis

- To describe the pattern of formal relationships in the network focusing on the aspects of co-ordination, collaboration and co-operation.

- To identify the distinctive characteristics of the network that may explain areas of strength and weakness in operation.

- To collect perceptions of the functioning of the network and the quality of the service from network members.

Respondents

33 members (42%) completed the questionnaire. 88% were doctors and nurses, the most common of whom were nurses and consultant paediatricians. Others well represented were directors/heads of care, clinical team leaders and medical officers. A few finance and managerial staff also responded.

The majority of respondents (80%) had been members of the network for one to six years with a range of less than one year to 12 years. Only 6% of respondents had joined the network in the last year. Almost 70% of respondents said they attended most or every meeting and where they couldn't attend they stayed in touch by email or face to face contact.

Representation

Many reported organisations and services that were not represented in the network, including adult palliative care services, social care, disabled children's services, commissioners, education, ambulance, local authority, special school education, Marie Curie services and some children's hospices. Individuals identified as having the potential to make valuable contributions to the network included acute sector consultants and allied health professionals, ambulance personnel, GP commissioners and service users. Many commented that membership of the network increased their ability to represent service users. Some mentioned specific examples of service user requests to the network (e.g. for complementary therapies) and areas of work needed, such as transition of young people into adult services. One respondent wrote:

> *Hopefully service users will be representing themselves at future (WMPPC) Network meetings.*

Support for networking

More than 80% of respondents said that their organisation supported their membership. Seventeen respondents were given time to attend meetings by their organisations and time and support to disseminate information and tools provided by the network. Over 60% were also members of other related networks. These included other children's networks (e.g. safeguarding, children's oncology, and Community Children's Nursing network), other West Midlands networks (e.g. WM Paediatric Network, WM Long-term Ventilation Network, WM Children's Cancer Network) and other local networks both outside and inside the West Midlands (e.g. North Wales Paediatric Palliative Care Network and Coventry and Warwickshire Multiagency Strategic Network for Paediatric Palliative Care).

Positive change of clinical Practice

> *I... have gained knowledge of the network, resources and management of children with life-limiting illness.*
> **(GP)**

> *...bringing information directly from practising clinicians into commissioning.*
> **(Commissioner)**

The majority (91%) said they had acquired new ideas, information or evidence about paediatric palliative care from the network.

- 74% said that their practice had changed as a result of belonging to the network, through new ideas (25), the toolkit developed by the network (9) and the advanced care plan also developed by the network (2).

- Improved knowledge was cited by a number of respondents.

One respondent said they were:

…more aware of how our particular hospice fits into the wider West Midlands area which will definitely enhance collaborative working with the statutory sector and voluntary sector colleagues.

Positive resources and opportunities

60% (20) of respondents commented positively on access to resources. One stated:

The joint bid by the network for palliative care monies for regional training would not have been available to a single Palliative Care Trust (PCT).

- 70% of respondents said that since joining the network they had had access to information about funds that they might not otherwise have heard about.
- Eight respondents mentioned the Department of Health (DH) £30 million service development programme.
- 67% had heard about jobs or courses through the network.

Seventeen respondents made comments about career related opportunities, 11 about courses, many very positively about communications courses. E-learning was also mentioned, specifically a web-based palliative care course.

Influence

My Trust gives greater credence to quality standards that have the backing of the network.

(Network member)

...it often carries more weight if one can demonstrate appropriate stakeholder collaboration; the network provides a good mechanism for demonstrating this.

(Network member)

The majority of network members responding (88%) felt they had more influence on:

- Practitioners, commissioners and policy makers (figure 8).
- Strategic Health Authorities, GP Consortiums and third sector groups.
- Membership added to their job role, contacts and reputation to enable them to exert influence (80%). Examples included securing funding, joined up working and effective lobbying of commissioners.

Eleven respondents gave examples of influence attributed to both membership of the network and job role, some naming specific forums which were influenced, the value of a 'collective voice' and 'credibility within my own area'. Fifteen respondents gave examples of other benefits, including speed of response to calls for pilot studies (for example, the DH £30m programme), involvement in the Big Study, membership of subgroups, lessening of isolation and improved knowledge and access to information.

As a member of the network do you feel you are able to influence any or all of the following groups?
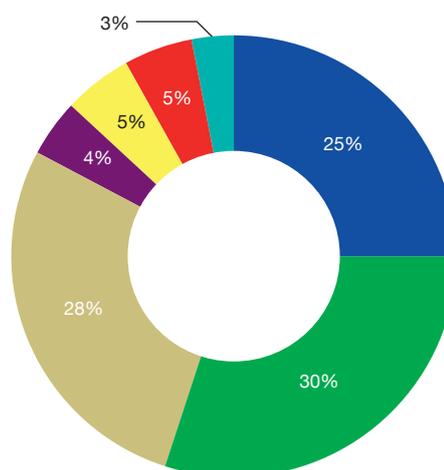
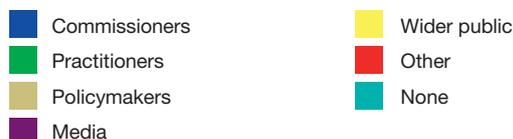94 reponses in total, respondents could choose more than one option.

- Commissioners
- Practitioners
- Policymakers
- Media
- Wider public
- Other
- None

Figure 8: Perceived influence of the network over groups

One respondent said they were:

…confident to offer home as a place of death knowing there was a wealth of knowledge at the press of a button.

Constraints and Contributions

…it can feel intensely political at times.

(Network member commenting on negative aspects of the network)

Few commented negatively: only four mentioned the time consumed especially where membership was 'additional to existing commitments'.

The vast majority of respondents:
• Felt no constraints (97%), less than 20% identified any negative aspects to membership.

• Had been able to make a contribution to the network (80%).

Most other comments (21) concerned membership of subgroups that drive change and contributing to bids for funds. Discussions at meetings 'where you feel valued' were also important.

Benefits for service users
Twenty-two respondents commented on the benefits to service users of the network.

• Indirect benefits were identified such as shared values and collaborative working which were perceived as enhancing consistency and standards through better informed, uniform care.

• Direct benefits mentioned were, 'the toolkit', more integration of services and partnership working.

Professional and social relationships

...meeting people face to face does foster better professional relationships.
(Network member)

Most (94%) said that they had developed new professional relationships through the West Midlands Paediatric Palliative Care Network. Less than 20% had made new social relationships.

Six (out of 22 commenting) gave examples of professional relationships developed in team working. Closer working with community teams and the voluntary sector were mentioned, and the meetings of lead nurses, coming together to look at provision of 24/7 care across the West Midlands.

Results of the network analysis
We gathered network data from 22 people in total. We asked four questions:

• Who do you know?

• Who would you go to for advice?

• Who provides leadership in the network?

• Who is influential outside the network?

Diagrams: Red nodes (spots) indicate an interviewee, blue nodes indicate another network member not interviewed. The lines represent the connections between the interviewees and the network members. Size of the node is proportional to the number of interviewees who identify the network member in relation to the question asked (in-degree).

Charts: Frequencies on the vertical axis represent the number of network members identified in relation to the question. The horizontal axis represents the individuals interviewed. For example on the frequency chart below (figure 9), individual no. 3 has identified 5 members of the network he or she knows.

Who do you know?
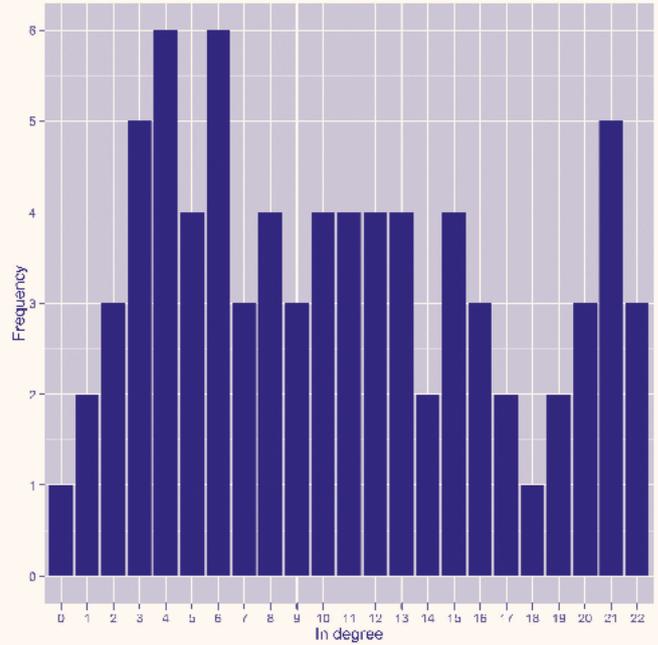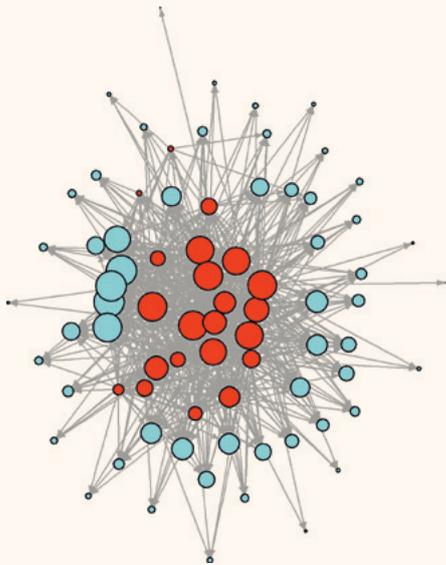
Number of members known by each interviewee

Figure 9: Network analysis diagram, Who do you know? And chart, Number of members known by each interviewee

Figure 9 shows a diagram of the network. There was one "isolate" i.e. someone who was not known to any of the interviewees – we have removed this person from the diagram. There are quite a number of people in this network who are known by many of the interviewees and a significant proportion who are known by only a few interviewees. This suggests that a core and periphery model might fit the data.

Who would you go to for advice?
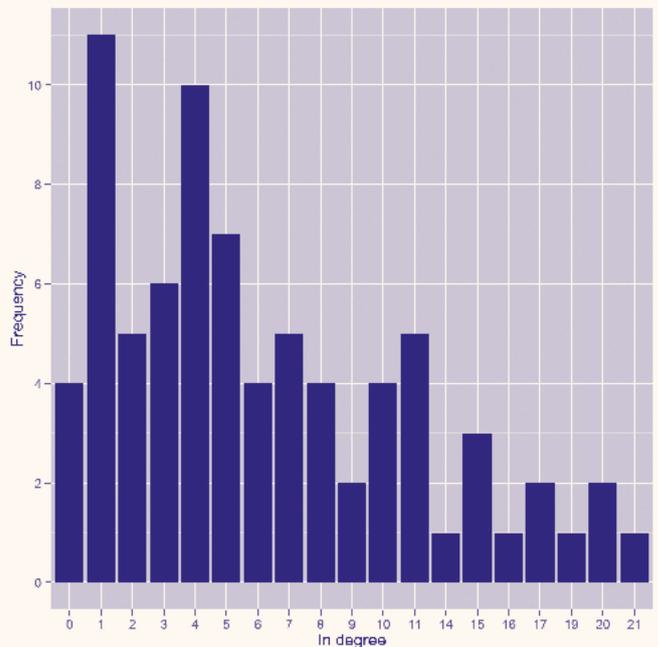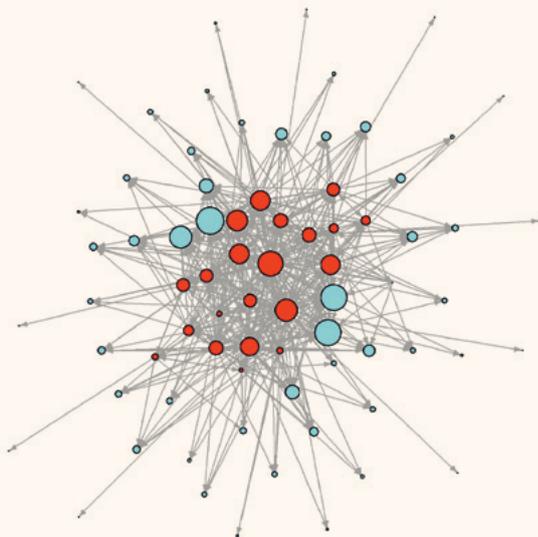
No. of members identified for advice by each interviewee

Figure 10: Network analysis diagram, Who would you go to for advice? And chart, Number of members identified for advice by each interviewee

There were only four people whom the interviewees would not go to for advice (figure 10, [chart] column 0). Most people in the network give advice to a few people and some might be asked for advice at some time by all the interviewees (in figure 10 [diagram] most interviewees identified four people who were not interviewed [blue spots] and seven interviewees [red spots]). This suggests that the network is drawing on expertise quite widely across the membership and may mean that individuals are seen to have specialist expertise or personal qualities that are valued in the course of decision making. The high density of ties in this network suggests alternative pathways by which information and knowledge travels around the network.

Who provides leadership?

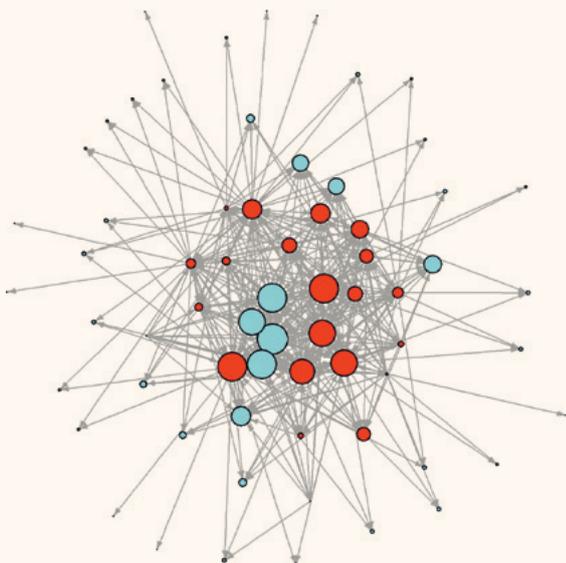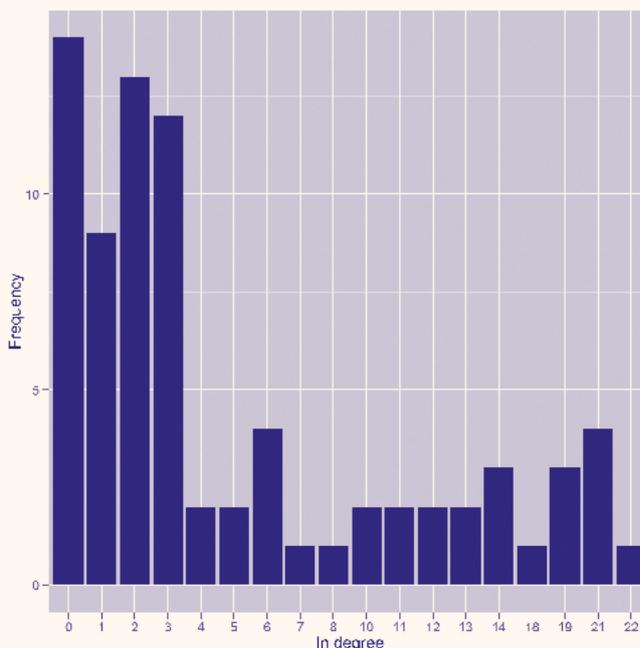**Number of leaders identified by each interviewee**

Figure 11: Network analysis diagram, Who provides leadership in the network? And chart, Number of members identified as leaders by each interviewee

Figure 11, shows about nine members (of whom five were interviewees) recognised as leaders by most, although most interviewees recognised different individuals. Three individuals identified a large number of leaders

(figure 11, chart). There may be a difference between strategic leaders and those described by one interviewee as 'movers and shakers' who are most influential through helping the sub-groups to achieve their goals.

Who is influential outside the network?

Number of members seen as influential outside the network, by each interviewee
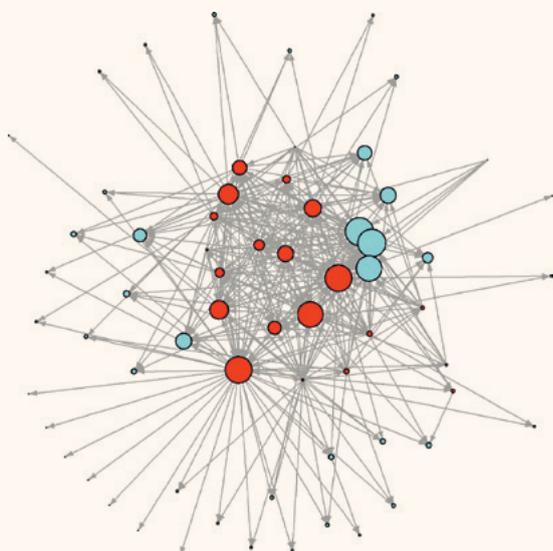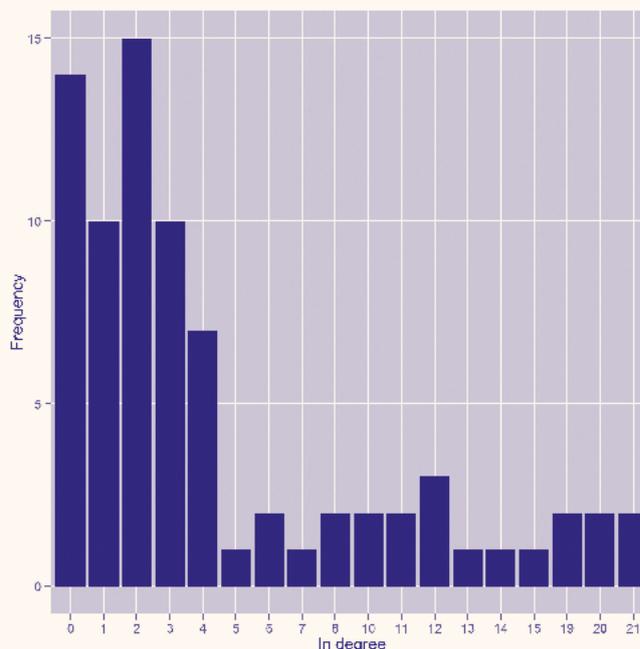
Figure 12: Network analysis diagram. Who is influential outside the network? And chart, Number of members identified as influential by each interviewee

The majority of people that were known to the interviewees were seen to be influential outside the network, with only 14 people seen as not being influential by all the interviewees (figure 12 [chart] column 0) and a few were seen as influential by almost all (the six larger nodes in

figure 12). Again this suggests that many of the members of the network are seen to be high profile in paediatric palliative care outside of the local area and may have a national or an international profile.

Summary

Initial network analysis suggests that this network is densely connected, with a core and periphery structure. It appears relatively decentralised with many people being seen as sources of advice, leadership and influence.

Potential areas of development for the network in co-ordination, communication and collaboration were in extending representation to all health, social care and third sector organisations providing services to children needing palliative care, as well as service users.

In order to improve communication and visibility, a network website could allow service users more access to the network with questions and suggestions.

The majority of members felt that they had contributed to the network. Key benefits that members derived from the network were:
- Obtaining new ideas to improve practice

- Access to resources

- New professional relationships

- An increased sense of efficacy and ability to represent service users

Conclusions

The findings from this study suggest that many of the claims about networks that appear in the policy and management literature are justified, at least in this case. Respondents described many ways in which they had benefitted from membership of the network, and few reported any disadvantages of membership apart from the time required to be a member. This study could contribute not only to the development of this network and may also be relevant to the development of networks in other areas of healthcare. Further analyses of these data will investigate what they can tell about the links between and among organisations involved in paediatric palliative care in the West Midlands as well as the distinctive roles that nurses and doctors occupy in the network structure.

Strand 4: Exploring the costs of care to providers and families

Introduction

The literature review found that there are very few economic studies of models of care for children and young people with life-limiting conditions. Those that do exist do not necessarily reflect the full costs falling on families. So while models of care such as hospice and community-based care may appear cost effective, the costs that families have to bear are not always considered in making these models work. For example, costs for a range of everyday and recurring items, including food, clothing, travel and heating and less regular but more expensive costs such as housing and vehicle adaptations. This additional cost burden is made more difficult to bear, in many cases, when parents and carers are unable to continue to work, either completely or partially.

Children and young people with life-limiting conditions tend to have multiple co-morbidities, that is they have a primary diagnosis with a particular condition but they may also be susceptible to other conditions in addition to, or as a result of, their primary condition. Care for these children and young people is an ongoing, complex process and there is no simple pathway of care that can be observed. Each child has their own pathway of care and alongside scheduled care such as tests and follow-ups, they will have unplanned episodes of illness. This means that existing sources of data on the costs of care, such as Hospital Episode Statistics and NHS reference costs, cannot be used to provide general ranges of costs for particular conditions. The analysis of costs therefore relied primarily on the data on episodes of care for children, recorded by carers and families during the time of the study.

Additional costs to families
We classified additional costs to families as 'one-off', non-recurring costs, ongoing or recurring.

- Non-recurring costs were those for wheelchairs, home adaptations, mobility aids and hoists, vehicle adaptation or leasing and other equipment.

- Recurring costs were those for nutrition and diet, special clothing and laundry, transport and travel, parking and heating.

Families provided either annual costs or monthly or weekly estimates, these were all annualised. Median costs are reported rather than mean costs because of the large range of costs reported.

More than half the respondents stated that they had incurred additional costs for heating and around a third or more reported this for equipment, special clothing and laundry, transport and travel, parking and home adaptations.

Many of the figures included in this chapter represent costs as presented from the perspectives of the families receiving care and treatment. They do not present an exhaustive estimate of all of the costs of providing services for children with life limiting conditions, but instead give a picture of the cost burden to services for providing this care, as reported by the families themselves.

Recurring costs
Table 17 provides details of the families who indicated that they incurred additional recurring costs as a result of caring for a child with life-limited conditions. The additional costs were estimated at around £264,000 per year for the population.

Table 17: Respondents reporting additional recurring costs

Cost category	Number	Median cost (£)	Cost range (£)	Total cost (£)
Nutrition and diet	30	780	20-2,600	28,590
Special clothing and laundry	64	390	50-10,000	41,363
Transport and travel	56	675	60-10,400	93,580
Parking	37	300	40-3,000	15,605
Heating	68	400	20-12,000	57,930
Other	35	520	180-5,200	26,720
Total				**263,788**

Respondents described some of the elements of the additional recurring costs that they had recorded:

- **Nutrition and diet:** Respondents referred to a variety of different supplements that they needed to buy for their children e.g. Omega 3. Both high (ketogenic) and low fat diets were referred to as well as specific items such as boxed milk. Some carers also referred to an increased food intake for their children, particularly when taking steroid-based medicines.

- **Special clothing and laundry:** Respondents referred to additional costs of cleaning clothes and bedding due to incontinence and also staining caused by chemotherapy. Carers reported having to buy larger sizes of clothing to fit nappies and additional footwear.

- **Transport and travel:** The main expense referred to was in relation to regular trips to hospital or clinics, either by car, train or taxi. Some respondents also referred to additional costs of travelling outside the region, for example to London to see specialists.

- **Parking:** Respondents reported additional costs in relation to visits to hospital.

- **Heating:** Some respondents referred to the need to keep their house warmer than usual due to their child's condition. Some also referred to the need to keep the heating on during the day or overnight for carers.

- **Other costs:** Thirty-five respondents reported costs aside from those covered by the headings in the survey such as nappies, additional play equipment and entertainment for their children, including toys, DVDs and video games, as well as trips to the theatre and cinema.

Disease category: Figure 13 shows a breakdown of the total additional recurring costs by the type of diagnosis of the child with a life-limiting condition in order to find out if some types of condition were more costly for families than others.
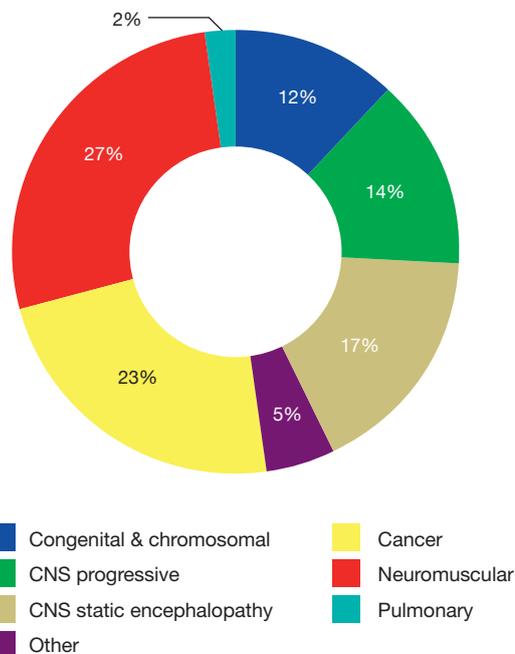

Figure 13: Additional recurring costs by type of diagnosis

- The highest proportion of additional recurring costs and the highest averages associated with their child's condition were incurred for the families with a child falling into the cancer and neuromuscular disease categories.

Table 18: Average additional recurring costs by disease category

Cost category	Total reported cost (£)	Number of respondents	Average cost per respondent (£)
Congenital & chromosomal	31,580	47	672
CNS progressive	37,850	26	1,456
CNS static encephalopathy	44,375	37	1,199
Cancer	62,015	31	2,000
Neuromuscular	70,648	31	2,279
Pulmonary	4,260	8	533
Other	13,060	8	1,633
Total	**263,788**	**188**	**1,403**

The average cost per respondent only provides an illustration of the disease categories that had the highest additional costs. It is important to stress that costs for individual families vary depending on the type and severity of the condition that their child has.

Non-recurring costs

Non-recurring costs are generally those costs that are not incurred on a frequent basis. However, there is no indication of when the costs were incurred. A housing adaptation that took place ten years ago will cost considerably less than if it was being paid for now. The only category that has not been reported is that for wheelchairs, where the costs and data specifications were considered to be unreliable by the Parent Carer Advisory Group.

Table 19 provides details of the numbers of respondents who indicated that they incurred additional non-recurring costs as a result of caring for a child with a life-limiting condition. The additional costs were estimated at almost £1.4 million over the population of the study.

Table 19: Respondents reporting additional non-recurring costs

Cost category	Number	Median cost (£)	Cost range (£)	Total cost (£)
Adaptations at home	48	7,000	300-200,000	870,250
Mobility aids and hoists	26	230	70-45,000	57,900
Vehicle adaptation or leasing	42	4,400	350-50,000	406,379
Other equipment	47	650	50-14,000	60,966
Total				**1,395,495**

Respondents described some of the elements of the additional non-recurring costs that they had recorded:

- Adaptations at home: Some respondents referred to major structural changes to their homes to add or extend bedrooms and bathrooms. Respondents also referred to enhancements made to outdoor areas such as gardens.

- Mobility aids and hoists: Respondents cited specific expenditure on a stairlift, a mobile hoist and slings.

- Vehicle adaptation or leasing: Respondents referred to adaptation of their car to accommodate a wheelchair and a number referred to having to buy additional and expensive vehicles as a result of their child's condition.

- Other equipment: Respondents reported a wide range of equipment that they had purchased in relation to their child's condition, including bicycles, a soft play room, a walker, a specialist bed, ramps, a sensory room, special chairs and coagulation and saturation monitors.

- Half of the total additional costs (not including wheelchairs) were incurred by families of children with CNS static encephalopathy.

- A quarter of the total additional costs were incurred by families of children with neuromuscular conditions (Table 20).

Table 20: Average additional recurring costs by disease category

Cost category	Total reported cost (£)	Number of respondents	Average cost per respondent (£)
Congenital & chromosomal	141,240	47	3,005
CNS progressive	211,400	26	8,131
CNS static encephalopathy	640,846	37	17,320
Cancer	37,290	31	1,203
Neuromuscular	362,019	31	11,678
Pulmonary	1,100	8	138
Other	1,600	8	200
Total	**1,395,495**	**188**	

As for the recurring costs, the average cost per respondent only provides an illustration of the disease categories that had the highest additional costs. It is important to stress that costs for individual families vary depending on the type and severity of the condition that their child has.

The data provided by respondents in relation to wheelchair costs were not considered to be accurate enough for reporting. The Muscular Dystrophy Campaign reports that the true average cost of providing an adequate powered wheelchair for a child with a life-limiting condition is in the region of £17,500 (Muscular Dystrophy Campaign, 2009).

Reduced employment

Loss of earned income was quantified using the national average annual wage (ONS, 2011).[3] One-hundred and thirteen (60%) respondents reported that either they or their partner, or both, had lost earned income as a result of caring for their child. The median amount of time lost reported was three months, a loss of £6,525 per family. The total annual lost income through reduced employment for the cohort of families who responded was estimated at over £1 million. This breaks down as follows:

Table 21: Average reported loss of income by disease category

Diagnostic category	Total reported loss of income (£)	Number of respondents	Average loss of income per respondent (£)
Congenital & chromosomal	282,533	47	6,011
CNS progressive	81,563	26	3,137
CNS static encephalopathy	133,001	37	3,595
Cancer	314,831	31	10,156
Neuromuscular	125,824	31	4,059
Pulmonary	24,469	8	3,059
Other	64,141	8	8,018
Total	**1,026,362**	**188**	

Parents and carers of children and young people with cancer reported the largest loss of earned income as a result of their child's condition.

Table 22 indicates the percentage of families who reported that they were in receipt of benefits:

Table 22: Percentage of families in receipt of benefits

Families in receipt of:	Percentage
Disability benefit	63
Carer allowance	58
Mobility allowance	39
Housing benefit	15
Supplementary benefit	4

The costs of hospital inpatient care

Families were asked to record the episodes of care that their children received over a period of six months. Around half of respondents reported a range of reasons for admission to hospital. These included various infections, viruses, gastrointestinal complaints, sleep studies, insertions of enteral feeding tubes, investigations and tests, fractures and surgery. The costs of inpatient stays for each diagnostic category were as follows:

Table 23: Estimated costs of inpatient care in hospital by diagnostic category

Diagnostic category	Number	Cost (£)	Average (£)
Congenital & chromosomal	47	283,901	6,040
CNS progressive	26	124,806	4,800
CNS static encephalopathy	37	138,212	3,735
Cancer	31	416,453	13,434
Neuromuscular	31	93,134	3,004
Pulmonary	8	45,521	5,690
Other	8	45,521	5,690
Total	**188**	**1,147,548**	**6,104**

Costs were extrapolated for a year and an average calculated. The results indicate that the cancer diagnostic category incurs a higher inpatient care cost than the other diagnostic categories. It is important that these results are treated with caution as they are likely to be sensitive to changes in incidence and unit costs. For example those diagnostic categories with higher average costs may be the result of one or two children who experienced atypical levels of illness during the six month period.

The cost of inpatient care for the lower income group was lower than that for the higher income group (Table 24).

Table 24: Estimated median costs of admission to hospital by income group

Income group	Number of people responding	Median cost (£)
Under £30,000 per year	60	3,195
Over £30,000 per year	26	7,490

3. £26,100 was the median gross annual earnings for full-time employees in April 2011 (ONS, 2011).

Across the PCT clusters, Arden had the highest costs and the Black County the lowest costs (Table 25).

Table 25: Estimated median costs of admission to hospital by PCT cluster

PCT cluster	Number of people responding	Median cost (£)
Arden	11	6,681
Birmingham and Solihull	23	4,772
Black Country	17	3,050
Staffordshire	18	3,579
West Mercia	15	5,726

Numbers of children in the Black, Mixed and Other ethnic group were too small to report. The estimated median costs for the White British group was £4004 (n=67) and for the South Asian group was £4772 (n=14).

Inpatient care

Factors on the Measures of Processes of Care (MPOC) survey were used to separate out two groups, those scoring at the high end for each factor (top 25%) and those scoring at the low end (bottom 25%). The middle 50% were excluded from this analysis. The MPOC factors are shown in the Table 26. Hospital inpatient costs are compared between the two groups (Table 26).

Table 26: Estimated median costs of admission to hospital by MPOC category

MPOC factors	Least positive		Most positive	
	n	Median cost	n	Median cost
Enabling and partnership	22	6,204	24	4,772
Providing general information	21	11,121	27	3,340
Providing specific information	22	5,726	24	2,863
Co-ordinated and comprehensive care	21	5,726	23	4,772
Respectful and supportive care	22	4,865	20	4,772

Outpatient care

Outpatient follow-up visits may be scheduled as part of a child's ongoing care for their condition or as a result of an inpatient episode for a complication. Most of the 137 respondents whose children had attended outpatient clinics in the last six months reported the nature of those clinics, such as examinations for respiratory conditions or routine clinics for ENT check-ups. These clinics were categorised into specialties and reference costs were applied to calculate the overall costs, detailed in Table 27 below:

Table 27: Estimated costs of outpatient care by diagnostic category

Diagnostic category	Number	Cost (£)	Average (£)
Congenital & chromosomal	47	33,512	713
CNS progressive	26	13,969	537
CNS static encephalopathy	37	15,162	410
Cancer	31	58,673	1,893
Neuromuscular	31	7,382	238
Pulmonary	8	3,885	486
Other	8	7,665	958
Total	**188**	**140,248**	**746**

There was a significantly higher cost burden associated with cancer patients. This appears to relate to the number of clinics and outpatient appointments these children have, rather than increased costs of the clinics themselves. This is shown as a proportion of overall costs in Figure 14 (p.50).

- There were no real differences in the cost of outpatient care to services between the higher income (over £30,000) and lower income group (below £30,000).

- Arden PCT cluster showed the highest outpatient cost (Table 28).

Table 28: Estimated median costs of outpatient care by PCT cluster

PCT cluster	Number of people responding	Median cost (£)
Arden	15	1,050
Birmingham and Solihull	36	630
Black Country	27	630
Staffordshire	30	475
West Mercia	23	420

Numbers of children in the Black, Mixed and Other ethnic group were too small to report. The estimated median costs for the White British group was £525 (n=105) and for the South Asian group was £630 (n=21).

In contrast to the earlier inpatient analysis by MPOC category, these costs are more similar between the groups, although there is a slight tendency for costs to be higher (more visits) for the more positive groups (Table 29).

Table 29: Estimated median costs of outpatient care by MPOC category

MPOC category	Least positive		Most positive	
	n	Median cost	n	Median cost
Enabling and partnership	25	525	37	735
Providing general information	29	735	40	630
Providing specific information	27	532	37	630
Co-ordinated and comprehensive care	27	525	37	735
Respectful and supportive care	30	531	32	739

Diagnostic and routine testing
Children with complex conditions often are subject to numerous and frequent tests including blood and urine, x-rays, MRI and CT scans. The estimated costs of diagnostic tests were:

Table 30: Estimated costs of diagnostic tests by diagnostic category

Diagnostic category	Number	Cost (£)	Average (£)
Congenital & chromosomal	47	8,396	179
CNS progressive	26	3,339	128
CNS static encephalopathy	37	4,657	126
Cancer	31	28,689	925
Neuromuscular	31	2,255	73
Pulmonary	8	2,057	257
Other	8	1,055	132
Total	**188**	**50,448**	**268**

Cancer patients had the highest average costs in relation to diagnostic and routine tests and those with neuromuscular conditions the least (shown as a proportion in figure 16).

Overall hospital based care
The overall annual cost burden for hospital based care, for the cohort of children and young people whose families responded to the survey was around £1.34 million. This was calculated by aggregating the costs of inpatient and outpatient care, along with the costs of diagnostic tests. This breaks down as follows:

Table 31: Estimated overall costs of hospital care by diagnostic category

Diagnostic category	Number	Cost (£)	Average (£)
Congenital & chromosomal	47	325,809	6,932
CNS progressive	26	142,114	5,466
CNS static encephalopathy	37	158,031	4,271
Cancer	31	503,815	16,252
Neuromuscular	31	102,771	3,315
Pulmonary	8	51,463	6,433
Other	8	54,241	6,780
Total	**188**	**1,338,244**	**7,118**

The cancer diagnostic category had the largest estimated cost (Figure 14) and also the highest average cost per child.
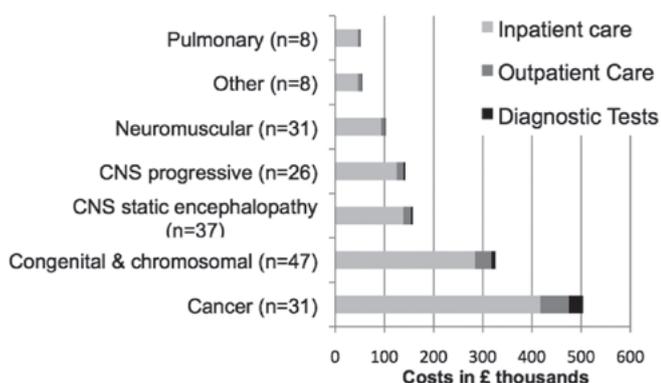

Figure 14: The costs of hospital-based care by diagnostic category

The costs of other care
Data about other care included: Community Children's Nursing Teams, GPs, clinical psychologists, allied health professionals such as physiotherapists, speech and language therapists and occupational therapists.

The costs of this care are shown in Table 32, estimations used standard costs[4].

Table 32: Estimated costs of other care by diagnostic category

Diagnostic category	Number	Cost (£)	Average (£)
Congenital & chromosomal	47	32,908	700
CNS progressive	26	39,836	1,532
CNS static encephalopathy	37	51,131	1,382
Cancer	31	43,398	1,400
Neuromuscular	31	33,048	1,066
Pulmonary	8	3,280	410
Other	8	8,656	1,082
Total	188	212,257	1,129

Respondents who were carers of children and young people in the cancer, CNS progressive and CNS static encephalopathy categories had higher average costs than other diagnostic categories.

The costs of short breaks
Short breaks were provided by hospices and other specialist units and included holidays. They could be funded by the family or by financial assistance. It was not clear from the data whether families had incurred these costs themselves or whether they received funding from any source. Nevertheless, from an economic perspective, they are additional costs associated with the child's life-limiting condition. The costs were calculated using PSSRU data and other data derived from the literature.

Table 33: Estimated costs of short breaks by diagnostic category

Diagnostic category	Number	Cost (£)	Average (£)
Congenital & chromosomal	47	211,850	4,507
CNS progressive	26	78,592	3,023
CNS static encephalopathy	37	135,640	3,666
Cancer	32	79,224	2,476
Neuromuscular	30	87,484	2,916
Pulmonary	8	0	0
Other	8	1,184	148
Total	188	593,974	3,159

The average costs of short breaks for families and children with congenital conditions and chromosomal disorders were higher than those of the other categories. Children in this group often have complex needs requiring specialist care during their respite periods.

Extrapolating the costs of care over the West Midlands

Costs to families
The estimated costs for the families within the survey to the wider population numbers were extrapolated to the population identified by the MDS. The following tables summarise the cost of care for the children and young people identified over the West Midlands.

Table 34: Estimate of additional recurring costs for West Midlands families

Diagnostic category	Total population	Respondent population	Respondent costs (£)	Total costs (£)
Congenital & chromosomal	297	47	31,580	199,559
CNS progressive	175	26	37,850	254,760
CNS static encephalopathy	271	37	44,375	325,017
Cancer	148	31	62,015	296,072
Neuromuscular	135	31	70,648	307,661
Pulmonary	62	8	4,260	33,015
Other	92	8	13,060	150,190
Total	**1,180**	**188**	**263,788**	**1,655,691**

The overall additional cost burden to families in the West Midlands is estimated at more than £1.65 million per year.

Table 35: Estimate of additional non-recurring costs for West Midlands families

Diagnostic category	Total population	Respondent population	Respondent costs (£)	Total costs (£)
Congenital & chromosomal	297	47	141,240	892,517
CNS progressive	175	26	211,400	1,422,885
CNS static encephalopathy	271	37	640,846	4,693,764
Cancer	148	31	37,290	178,030
Neuromuscular	135	31	362,019	1,576,534
Pulmonary	62	8	1,100	8,525
Other	92	8	1,600	18,400
Total	**1,180**	**188**	**1,395,495**	**8,758,958**

Families incur estimated costs of more than £8.5 million for items such as additional equipment or adaptations (not including wheelchairs).

Table 36: Estimate of loss of income for West Midlands families

Diagnostic category	Total population	Respondent population	Respondent costs (£)	Total costs (£)
Congenital & chromosomal	297	47	282,533	1,785,368
CNS progressive	175	26	81,563	548,982
CNS static encephalopathy	271	37	133,001	974,142
Cancer	148	31	314,831	1,503,064
Neuromuscular	135	31	125,824	547,943
Pulmonary	62	8	24,469	189,635
Other	92	8	64,141	737,622
Total	**1,180**	**188**	**1,026,362**	**6,442,059**

Families have collectively lost nearly £6.5 million in income per year through having to reduce or give up employment, albeit with some families claiming additional benefits to offset loss.

Costs to care services

The same process was applied to the costs of care to extrapolate total costs for the West Midlands.

Table 37: Estimate of total hospital costs for West Midlands families

Diagnostic category	Total population	Respondent population	Respondent costs (£)	Total costs (£)
Congenital & chromosomal	297	47	325,809	2,058,836
CNS progressive	175	26	142,114	956,537
CNS static encephalopathy	271	37	158,031	1,157,470
Cancer	148	31	503,815	2,405,310
Neuromuscular	135	31	102,771	447,551
Pulmonary	62	8	51,463	398,838
Other	92	8	54,241	623,772
Total	**1,180**	**188**	**1,338,244**	**8,399,617**

The estimated cost for hospital based care (inpatients and outpatients) is around £8.4 million.

Table 38: Estimate of other care costs for West Midlands families

Diagnostic category	Total population	Respondent population	Respondent costs (£)	Total costs (£)
Congenital & chromosomal	297	47	32,908	207,951
CNS progressive	175	26	39,836	268,127
CNS static encephalopathy	271	37	51,131	374,500
Cancer	148	31	43,398	207,190
Neuromuscular	135	31	33,048	143,919
Pulmonary	62	8	3,280	25,420
Other	92	8	8,656	99,544
Total	**1,180**	**188**	**212,257**	**1,332,251**

The estimated costs for primary and community care and the voluntary sector are around £1.3 million
The annual costs to public services of providing care and treatment for children and young people with life-limiting conditions in the West Midlands is estimated to be almost £10 million (taking hospital care and community care together). This figure represents the costs of the episodes of care as reported by the families, rather than the full costs of the health and other care services.

Table 39: Estimate of short break costs for West Midlands families

Diagnostic category	Total population	Respondent population	Respondent costs (£)	Total costs (£)
Congenital & chromosomal	297	47	211,850	1,338,712
CNS progressive	175	26	78,592	528,985
CNS static encephalopathy	271	37	135,640	993,471
Cancer	148	31	79,224	378,231
Neuromuscular	135	31	87,484	380,979
Pulmonary	62	8	0	0
Other	92	8	1,184	13,616
Total	**1,180**	**188**	**593,974**	**3,728,135**

The cost of short breaks is estimated at £3.7 million.

These costs are presented from the perspectives of the families receiving care and treatment. They do not present an exhaustive estimate of all of the costs of providing services for children with life-limiting conditions, but instead give a picture of the cost burden to services for providing this care, as reported by the families themselves. It is likely that these costs are incurred by the public and voluntary sectors as well as by families themselves. However, it is not clear in what proportion these costs are borne. The survey indicated that some families bear these costs themselves while others are able to access funding from a variety of sources.

Summary

Families have to bear costs for a range of everyday and recurring items, including food, clothing, travel and heating. They also have to pay for less regular but more expensive costs such as housing and vehicle adaptations.

For the survey respondents, the costs of recurring items was found to be more than £250,000 per year, which when extrapolated to the wider population in the West Midlands, came to an annual cost of over £1.65 million per year.

The survey respondents reported that they had spent nearly £1.4 million on non-recurring items and this did not take into account the costs of wheelchairs. This translated as a cost burden of £8.75 million across the West Midlands, in addition to the recurring daily costs of care. The Parent Carer Advisory Group reflected that they felt that this reported cost was likely to be an underestimate of general costs incurred on non-recurring items by families.

The total costs of hospital based care for survey respondents was estimated at over £1.3 million per year. This equates to an overall cost for the West Midlands of around £8.4 million per year.

Non hospital based care was estimated at over £200,000 per year or around £1.3 million across the West Midlands.

The cost of short breaks for families in the survey was estimated at nearly £600,000 per year or £3.7 million across the West Midlands.

It was not possible from the responses to ascertain the extent to which families had to bear these costs themselves, but some respondents indicated that they had received financial assistance from either the public or voluntary sectors.

Strand 5: Facilitating the involvement of parents, carers and young people

Introduction

In health and social care service provision there is emphasis on involving patients and the public in developing plans and making decisions about local services (DH, 2010) and organisations such as INVOLVE, encourage user involvement in health research in the UK. In relation to research, the aims are similar to involvement in service provision, with involvement aiming to enhance the quality and relevance of research (Research Design Services, 2010). The aim of the user involvement in the Big Study was to support and enable patient and public involvement in the planning and the conduct of the study to ensure its relevance to service users. In addition, the study aimed to assess the impact of patient and public involvement within the study and contribute to methodological development in understanding the difference involvement makes to research. The importance of context and process in developing the potential for impact of involvement has been recognised as vital in developing our understanding of the impact of public involvement more broadly. The Big Study is one of the first to explore these issues with families of children with life-limiting and life-threatening conditions.

Demographics and participation of service users

The Parent Carer Advisory Group included a 'core' group of five parents and carers who provided feedback on many aspects of the study. Members of the wider group, that included 12 parents and carers who had responded to our invitation, gave their views and responded to specific questions by telephone or email. The 'core' group included a grandparent who was a particularly active member, and the wider group included a foster parent (both carers for a child with a life-limiting condition). Four bereaved parents were members of the group, two of them in the 'core' group. The Big Study acknowledges the support of the National Institute for Health Research, through the contribution that members of the West Midlands Medicines for Children Research Network made to the Study. We did not collect details about the children who took part in discussions. Researchers from each of the five strands of the study attended one or more Parent Carer Advisory Group meetings. The meetings were facilitated by researchers who co-ordinated the service user involvement in the study and support was accessible for service users when required.

Results

We have identified some key context and process factors which were important in involving parents, children in the study and which have implications for future studies.

Payment and recognition

Payment and recognition of user involvement has been previously recognised as an important factor in the context underpinning involvement (Brett et al., 2010). Feedback indicates that payment was appreciated and affirmed the value of contributions. We took into account that in some contexts payment could discourage involvement because of the possible effect on benefits.

Responsiveness to personal and family circumstances

Families of children with life-limiting conditions need to balance multiple, complex, often unpredictable and stressful demands. Many of those who volunteered for groups found it difficult or impossible to attend meetings at specific times, even though they expressed a keen desire to help with the research in any way they could. To respond to their preferences and needs as productively and sensitively as possible, we developed processes in collaboration with individuals and also with the 'core' group within meetings. The Research Fellow spent time getting to know individual parents and carers and their particular interests and areas of expertise, and encouraged them to take part as much or as little as they wished in providing their feedback. Most conversations took place initially over the phone and then by email, though the Research Fellow also visited two families at home and two parents in their workplaces (at their suggestion). In later stages, she was then able to direct questions to family members with specific relevant expertise.

Ways of working – meetings with parents and carers

The importance of ways of working has been identified by a range of organisations including INVOLVE. Much less is written about the content of good ways of working in order to inform future practice. Parent Carer Advisory Group meetings were considered important, not only for attendees but also for members of the wider group of parents and carers. They provided a structure for involvement activities, a point of communication and a means of addressing issues in depth. There was very careful selection of meeting venues to ensure the location was convenient and to ensure the ambience of the meeting place was appropriate for the study and would enable parents to feel comfortable. The meeting time was limited to two hours (except for the longer final meeting) to fit in with other commitments and in recognition of the intensive nature of the proceedings. The Research Fellow leading on involvement facilitated each meeting with the aim of enabling contributions from the parents, so that all parents felt able to contribute, that everyone listened in a respectful way to others' contributions, that researchers had a chance to raise and discuss key issues and that all contributions were valued. In this way, we aimed to create an appropriate environment for contribution, with clear leadership from the facilitator to encourage discussion. Members of the wider group received details of discussions in advance of each meeting and after it, and some asked for specific items to be covered. It was helpful for researchers to meet parents and carers in person, especially for those who did not make face to face contact with families as part of their own strand of research. Parents and carers who attended meetings appreciated meeting each other on a regular basis, and built up a substantial amount of expertise about the study which informed their ongoing contributions.

Ways of working – remote contact with parents and carers

While some parents and carers were able to meet on a regular basis, with additional email contacts between meetings, some parents who wanted to be involved could not attend any of the meetings because of their other commitments. The Research Fellow worked with these parents to find other ways of communicating with them to ensure their input was integrated into the study wherever possible.

Ways of working – children and young people

Discussions with children took place in a family home and at meetings of the Medicines for Children Research Network (MCRN) group. A parent helped with the discussion in a family home, and facilitators of the MCRN group assisted with the MCRN group discussions.

It was helpful to be able to consult children from a family who had taken part in the Big Study, and also to access an established group who had associated experiences and who were already used to involvement in research. We asked for group members' views on the best ways for us to work with children, which informed our plans and conduct of later contact. We involved children in interpreting, commenting on, illustrating and prioritising the issues raised by family members on changes in services they would like to see. We also asked for their views on key messages and priorities for the Study as a whole. We encouraged group members to talk about their own perspectives on the subjects under discussion, and they responded with insight, sensitivity, humour, and a considerable amount of expertise. As with the parents' group, meetings were recorded (with participants' permission) and detailed notes were made and shared with other researchers so that members' contributions could be fully taken into account.

Feedback on the service users' involvement in the research process

> *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 Carer Advisory Group)**

Early involvement of parents and children helped shape the original bid. Families were consulted during the development phase to help inform the research questions to be investigated. However, due to delays in recruitment, the core Parent Carer Advisory Group was not established until the research was underway. Researchers should note that users expect some impact from their involvement and can be quite frustrated if involved late in the process, for instance in development of methods or instruments.

The children were especially interested in methods of gaining the views and experiences of people in their age group, and they suggested ways in which recruitment for advisory groups might be improved in future research projects, for example, by age-specific materials, online discussions, and use of You Tube videos.

Diaries provided a structure for individual participants to comment on positive and negative aspects of involvement. Members of the group found meetings interesting and useful.

> *…I can … give my opinions and know that I am being taken seriously.*
>
> **(Parent Carer Advisory Group member)**

> *I felt that … we gave a lot of important feedback and some findings were … understood more clearly as a result of our experiences.*
>
> **(Parent Carer Advisory Group member)**

> *…this group should be an ongoing one to regularly feedback and discuss how care is being delivered and to take actions to address the gaps that exist… [we] may have more influence if we went to the [research group] rather than they came here.*
>
> **(Parent Carer Advisory Group member)**

Feedback and diary entries completed by researchers included reflections on the involvement of service users.

> *It is really helpful to get some personal perspectives on the … data that we are processing.*
>
> **(Research team member)**

Feedback from service users on the findings of the study

Group members provided validation for most findings presented to them at the advisory meetings by the researchers attending, confirming that these resonated with their personal experiences and those of other families they knew. They added illustrative detail to less clearly specified responses, and they discussed unexpected results. They also corrected some potential misinterpretation of data (for example, on reasons for relatively low take-up of some benefits and on potential underestimates of costs).

The most intensive involvement took place in connection with the analysis and interpretation of qualitative responses to the open-ended questions in the survey, where families identified changes they thought could most improve services. For example, a key change suggested was better co-ordination of services, including the provision of information to families at appropriate times. Young people had a particular interest in communication, and bereaved parents were particularly concerned about the need for emotional support and the abrupt cessation of financial help for families after bereavement.

Better care for children, young people and their families – What does it look like?

The puzzle diagram shows eight pieces surrounding a central piece labelled "What does better care look like?":
- Communication and information
- Costs
- Co-ordination of care
- Collaboration and co-operation
- Centred on children, young people and families
- Caring for wellbeing
- Commonality and equity
- Competency and confidence
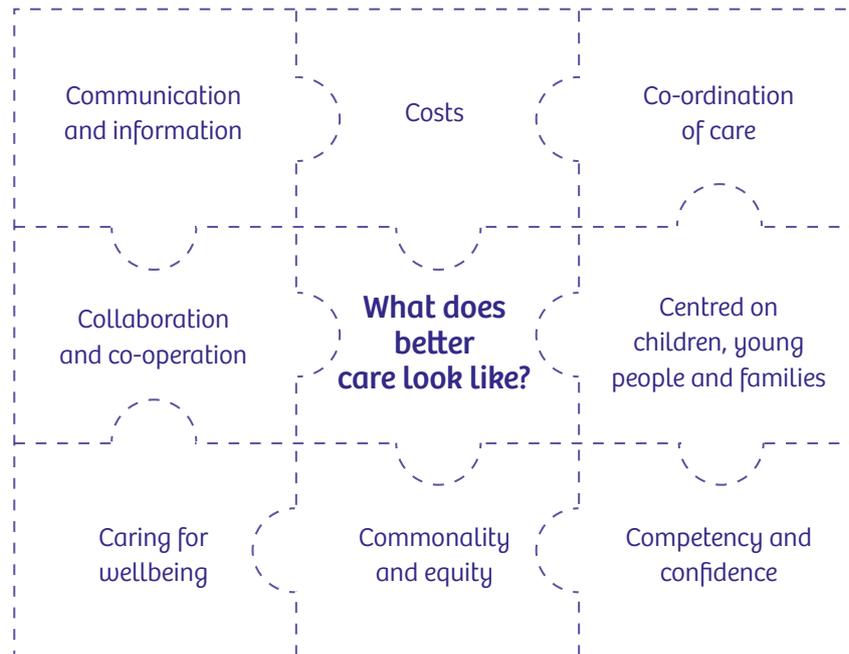
From the analysis of findings from the Big Study, it is possible to group elements of what 'better care' may look like under eight headings.

Better care looks like...

Communication and information for families

- All families should have equal access to information and advocacy services.

- Communication with children needs to be valued and opportunities 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 and their families.

- Information is clearly provided about the roles of different professionals.

Costs

- Financial support is equally 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.

- Ongoing research determines changes in family costs, including one-off expenses and costs for families on diagnosis, before, during and after bereavement.

Co-ordination of care

- Children 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 to adult services.

- More 24/7 care is available with quicker and smoother access to services.

- Good co-ordination 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 co-operation

- 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 parents' choice, taking account of what is important to each individual child and their families.

- Care packages are in place that are lifelong, and which meet the needs of the child and family.

- The centrality of the family's role in caring for a child with a life-limiting or life-threatening condition needs is recognised, with support needs met for the whole family.

- Parents and children are encouraged to actively participate in research studies, with feedback and/or action taken on their views.

Caring for wellbeing

- A regional service meets not only the physical needs but also the emotional and psychological needs of children and families, starting at the point of diagnosis and into bereavement for the family.

- Opportunities are provided to enable children 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

- A regional service exists on a 24/7 basis that is accessible, fair, comprehensive and flexible as the child's needs change.

- Ongoing research into the needs of children and families that represent the population informs planning.

- Improved regional delivery in respect of specialist speech and language therapy, physiotherapy and occupational therapy is available.

- Every child 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 and families.

- Professional staff (within health, social care and education) have improved skills, competency and confidence to care for and support children with life-threatening or life-limiting conditions and their families.

Recommendations for the future

The findings of the Big Study portray a clear vision of what better care for children, young people and their families should look like within the eight areas identified in the diagram on p.59. The following recommendations have been identified as priority actions to be taken by service providers:

Recommendations for service providers

1. 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. Financial advice and support must be provided to families as an essential component of a children's palliative care service.

3. Families must have a named individual to help them navigate the system to enable access to appropriate children's palliative care services in a timely manner.

4. Continued emphasis to improve collaboration and joined up communication within and across health, education and social care teams.

5. Recognition 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 must ensure they provide a range of support to meet the family's emotional, psychological and environmental needs, from diagnosis to bereavement, including provision of physiotherapy and occupational therapy.

7. Children's palliative care networks should establish sub-groups to focus on improving transition and service integration at an operational level.

8. 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-limiting or life-limiting conditions and their families.

Recommendations for work for Together for Short Lives

Some of the findings of the Big Study have highlighted specific areas of activity or further research that Together for Short Lives should consider for inclusion in their current or future strategic plans. Such areas of possible future activity include:

• Supporting the development of, and improved access to, information for children and families.

• Development of a training curriculum to support the professional development of all those working in children's palliative care.

• Supporting the development of robustly calculated and resourced commissioning models.

• Ongoing promotion of successful models that offer 24/7 care support in a co-ordinated and joined up way.

• Identifying opportunities for further qualitative research into the burden of costs to families with children with life-limiting conditions to understand how these costs affect them.

• Ongoing work through networks to strengthen co-ordination and collaboration in service planning and delivery.

Next Steps

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 with life-limiting or life-threatening conditions and their families.

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