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together for short lives

Count Me In: Children's Hospice Service Provision 2011/12

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Contents

Foreword

Once again, I am delighted to recommend to you the 2011/12 annual data mapping report, "*Count Me In*". This report has been produced by Durham University in partnership with *Together for Short Live*s. This work aims to contribute to the improvement of children's and young people's palliative care by further developing a systematic approach to the collection of information from children's hospice services as well as other third sector children's palliative care providers around the UK. Following the merger of Children's Hospices UK with ACT at the end of 2011, *Together for Short Lives* is the only national membership body that provides support to children's palliative care organisations, children and young people and their families across the UK.

Over the last two years, I have been working with the Department of Health England on an *Independent Funding Review* of both adult and children's palliative care services. We are now beginning to seek information and data to enable the creation of a fairer funding system for palliative care services for both adults and children and young people. We are developing an NHS tariff to meet NHS responsibilities, regardless of the choice of provider, on a per-patient basis. I am very aware of the challenges we face in addressing inequalities and the funding role of palliative and end of life care in an integrated health and social care system.

I believe that this rich and informative data mapping report will not only assist some of the palliative care funding review work being carried out in England but will also help commissioners and providers of other children's and young people's palliative care services, government offices and particularly those influencing the future of children's palliative care policy around the UK.

Alan W Craft

Professor Sir Alan Craft

July 6th 2012.

Acknowledgements

The Durham University team would like to thank the staff working within children and young people's hospice services and other third sector children's palliative care providers throughout the UK who have contributed to this data collection. It would not have been possible to produce this report without the time and effort taken by them to input the data and complete the exercise.

We would like to thank *Together for Short Lives* for their collaboration and support in this project. In particular we thank Maddie Blackburn for her ongoing assistance and guidance which has been valuable at every stage of the project. Thank you to members of the National Children's Palliative Care Data Forum who provided useful feedback on the questionnaire and other stages of the project, in particular Dr Lorna Fraser, Dr Lynda Brook and Dr Duncan Randall.

Thank you to Wilkinson for providing some of the funding for this work.

Executive summary

Introduction

The need for improved and consistent local and national data about the prevalence and needs of children and young people with life-limiting conditions and the palliative care services that support them has been recognised for some time (Craft and Killen, 2007; Department of Health, 2008; Health Challenge Wales/Welsh Assembly Government, 2008; Department of Health, Social Services and Public Safety, 2009; The Scottish Government, 2009; Children's Hospices UK, 2010; Fraser *et al,* 2011; 2012).

Data mapping project

This report presents the results from the 2011/12 children's hospice services data collection, carried out by a team at Durham University in partnership with *Together for Short Lives*. The project aims to contribute to the improvement of children's palliative care services by further developing a systematic approach to the collection of data from children's hospices in the UK. It also includes a feasibility study on collecting data from other third sector children's palliative care providers. (This is reported separately in the main report).

Key messages

In 2011/12, thirty-three out of thirty-five children's hospice providers in the UK participated in the data collection and submitted information on forty-three services[1] about types of provision and the numbers of children, young people and families they supported. It has also been possible to compare some of the information provided by 41 children's hospice services in the 2010/11 and 2011/12 data collection. As not all children's hospice organisations participated this year or can be compared over the two years, the results presented below should be read and interpreted with care[2]:

- In 2011/12, 43 children's hospice services supported **7,638** children and young people with life-limiting conditions[3] and **9,930** families (including bereaved families). Data from the 2010/11 and 2011/12 comparable children's hospice services[4] reported an **8%** increase in the number of children and young people supported (from **6,823 to 7,357**) and a **7%** increase in families supported (from **8,871 to 9,522**) between the two years.

- In 2011/12, children's hospice services received 2,316 referrals including 664 (29%) from community children's nurses, 324 (14%) from consultants and 274 (12%) from family members[5]. 1,731 referrals were accepted representing 23% of the children and young people supported by services during the data collection period. Neonates (newborn to 28 days) represented 8% of the referrals accepted and 2% of the children supported in the period. 7% of the referrals accepted

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[1] Six organisations provided more than one service and a questionnaire was completed for each service. The two organisations that did not participate did not have the capacity at the time of the data collection. The list of children's hospices in the UK can be found in Appendix A.

[2] Information on response rates and data issues for 2011/12 results and 2010/11 and 2011/12 comparable services can be found on pages 11 and 24 and should be read in conjunction with this summary. Please also note that inferences are not drawn from the comparable data to all children's hospices in the UK. Activity data in both years was reported for the 12 month period from 1st April to 31st March.

[3] This includes those supported by hospice at home or community outreach schemes and includes referrals accepted in the period. One service started delivering in January 2012 and therefore only had partial activity data.

[4] The figures are not the same as the totals reported for each year as they are only for those services comparable in 2010/11 and 2011/12.

[5] The referrals received percentages are calculated out of 2,288 as one service could only provide partial information on source of referral.

and 23% of those supported were 16 years old and over. The comparable services reported a 12% increase in the number of referrals received by children's hospice services and a 9% increase in referrals accepted from 2010/11 and 2011/12.

- In 2011/12, the ethnic origin of 21% of referrals accepted (n=1,731) and 22% of children and young people supported (n=7,638) were reported in the 'not stated' category. Data from comparable services indicate a 2% reduction (from 23% to 21%) in the children and young people supported whose ethnic origin was recorded as not stated from 2010/11 to 2011/12.

- The types of support delivered by children's hospice services to children, young people and families in 2011/12 were wide-ranging. All 43 reporting services provided end-of-life care, family support and sibling support and telephone advice and contact.

- In 2011/12, the total direct care team workforce reported by 43 services was 1,632 whole time equivalent (WTE)[6]. Nurses made up 51% of the workforce (830 WTE) and the second largest staff group was NVQ qualified healthcare workers accounting for 22% (365 WTE).

- While the comparable services reported an increase in the number of referrals received and children and young people supported between 2010/11 and 2011/12, a 4% decrease in the number of deaths in hospice care was also reported from 697 in 2010/11 to 666 in 2011/12. This represents 10% and 9% of children and young people supported respectively.

- The total number of deaths in hospice care in the 2011/12 period for 43 reporting services was 701. The location for over half of the deaths of children and young people were either in the home (33%) or in a hospice (21%) (6% were in an unspecified location and 40% in hospital).

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[6] Direct care team in post as of 31st January 2012.

1. Introduction

The need for improved and consistent local and national data about the prevalence and needs of children and young people with life-limiting conditions and the palliative care services that support them has been recognised for some time (Craft and Killen, 2007; Department of Health, 2008; Health Challenge Wales/Welsh Assembly Government, 2008; Department of Health, Social Services and Public Safety, 2009; The Scottish Government, 2009; Children's Hospices UK, 2010; Fraser *et al*, 2011, 2012). Recent work found the prevalence of life-limiting conditions in children and young people in England was more than double previous estimates and prevalence in Scotland, Wales and Northern Ireland was also higher than previously estimated (Fraser *et al*, 2011, 2012). The report from the Independent Palliative Care Funding Review, commissioned in July 2010, sets out the need for the systematic development of a robust children's data collection system to assist in building a per-patient funding tariff mechanism for palliative care in England (Hughes-Hallett, Craft and Davies, 2011). Although the proposed per patient funding tariff will only apply in England, we believe that it will also be of interest to the children's palliative care sector across the UK.

This report presents the results of the 2011/12 children's hospice service data collection project. The project continued the long-standing commitment of Children's Hospices UK (now *Together for Short Lives*) to collect information from their members to support strategic planning and the development of services to meet the needs of children and young people with life-limiting and life threatening conditions[7]. Children's Hospices UK has worked in partnership with a team at Durham University since 2009 on this annual data collection. In 2011/12, thirty-three children's hospice providers, out of thirty-five in the UK, participated in the data collection submitting information on forty-three services.

This data mapping project aims to contribute to the improvement of children's palliative care data by further developing a systematic approach to collecting and presenting robust information on children's hospice services in the UK. This includes information about the location and types of services provided and the children, young people and families that use the services. The purposes of the data collection include:

- Evidencing the support currently provided to life-limited children, young people and their families by children's hospices
- Describing the models of care provided
- Informing children's palliative care policy, commissioning, service planning and practice at local and national levels.

Online data tables and maps were first developed in the 2010/11 project to present the information collected in accessible and visual formats. This work has been developed further this year and can be accessed at http://childhospiceuk.dumu.org.uk.

Feasibility study on collecting data from other third sector children's palliative care providers

Following Children's Hospices UK's merger with ACT to establish *Together for Short Lives* in October 2011, eleven other third sector children's palliative care providers, offering services similar to children's hospices, were invited to participate in the data collection to test the feasibility of

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[7] At the time of completing this report, there is considerable debate about the definitions of life-limiting and life-threatened children. *Together for Short Lives* is engaged in work with national research and data groups to address this.

including this wider sector. Three other third sector children's palliative care providers completed the data collection, providing information on ten services. The results are summarised separately in section five of this report.

2. Service mapping methodology

2.1. Background

Durham University Mapping Unit developed a system for online data collection and reporting of children's services in 2002. Initially developed to record the provision of, and investment in, child and adolescent mental health services in England the system was expanded in 2005 to cover a broader range of child health and maternity services and in 2008 to enable local authorities to map their children's services. Information was collected annually about the types of services provided, their location, workforce and position in relation to a range of policy initiatives and was used by the Department of Health and regulators during that period.

Features of the service mapping methodology include:

- Questionnaires completed at the local level by people who provide the services
- Service provision linked to and reported by geographical area
- Data reported locally and aggregated to regional and national levels
- When completed as an annual exercise, year-on-year trends can develop.

In 2009 when Children's Hospices UK approached Durham University Mapping Unit for support with their data collection, the Unit was undertaking the annual Children's Services Mapping exercise for the Department of Health and the Department of Children, Schools and Families (now Department for Education). It was agreed that an online collection of children's hospice service data should be piloted through the 2009/10 national Children's Services Mapping exercise to test the feasibility of using this methodology for children's hospice services. The results of the data collection are reported in *Children's Hospice Service Provision 2009/10* (Children's Services Mapping with Children's Hospices UK, 2011). The lessons learnt and evaluation from the pilot exercise informed the proposal and development of the 2010/11 data collection which was funded by the Department of Health's *£30 million children's palliative care programme* and reported in *Children's Hospice Service Provision 2010/11* (Durham University Mapping Unit and Children's Hospices UK, 2011). After a successful 2010/11 collection Children's Hospices UK (now *Together for Short Lives*) again commissioned Durham University to carry out the 2011/12 data collection.

2.2. 2011/12 questionnaire development

The development of the service questionnaire for the 2011/12 data collection was informed by feedback from the 2010/11 collection, including data checks, and a participant evaluation. In addition, following consultation with the National Children's Palliative Care Data Mapping Forum, a new question was introduced about supporting technology dependent children and a new diagnostic categorisation was piloted (see page 16 and appendix C)[8]. In the main, questions were kept the same as 2010/11 with the aim of being able to compare data year-on-year where possible.

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[8] A new question was included for total deaths to help with data checking the breakdown of deaths by age bands and location. The breakdown of referrals received and children and young people supported by age and gender were asked as separate questions in 2011/12 as they were combined in 2010/11 and some organisations did not collect information on gender and were therefore unable to answer the questions.

2.3. Data collection process

The process of data collection involved a nominated lead from each organisation registering on the service mapping online system on behalf of their organisation. Organisations with more than one hospice service were requested to complete a questionnaire for each service. Completed 2010/11 questionnaires, apart from activity data, were migrated for those organisations that had completed the 2010/11 exercise. The lead needed to check that the information in the service questionnaire was still correct, amend if necessary and complete activity data for the period 1st April 2011 to 31st March 2012. Blank questionnaires were set up for organisations that were new to the exercise in 2011/12. Organisations who did not register were followed up on a number of occasions in an attempt to maximise participation in the data collection.

Towards the end of the data collection, online reports were set up summarising key fields of the data to facilitate the checking of the information entered. The reports were linked to a sign off process to indicate completion of the exercise. Participants were also directed to an evaluation questionnaire. The results of the evaluation of the data collection can be found in Appendix E.

The Durham University team carried out data checks on the staffing and activity data once organisations had signed off the exercise. Organisations were contacted if there was missing information or discrepancies with the data. This led to some amendments being made and gave organisations the opportunity to provide reasons and explanations for incomplete data and discrepancies. Checks were also carried out on comparable data and comparable organisations from the 2010/11 data collection. Organisations were asked to confirm where there were significant differences in the information between the two years and to amend if appropriate.

The results are set out in three sections:

1. **Children’s hospice services in the UK 2011/12.** This section presents the results from the 2011/12 data collection for children’s hospice providers in the UK (pp. 11-24).

2. **Comparable data for children’s hospice services 2010/11 and 2011/12.** This section compares information provided by 41 children’s hospice services in the 2010/11 and 2011/12 data collections and presents year-on-year information (pp. 24-28).

3. **Other third sector children’s palliative care providers feasibility study.** The final section of results summarises information from the feasibility study carried out with other third sector children’s palliative care providers (pp. 28-30).

Each section begins by outlining the response rates and the data issues to consider when reading the results.

3. Children's hospices services in the UK 2011/12

3.1. Response rates and data issues

Thirty-three children's hospice service providers in the UK, out of thirty-five, registered and signed off the 2011/12 mapping exercise. The two organisations that did not participate did not have the capacity at the time of the data collection. The list of children's hospices in the UK can be found in Appendix A. Forty-three service questionnaires were submitted as six organisations provided more than one service and completed a questionnaire for each service.

Changes in the services participating from the 2010/11 collection include one new service that started delivering at the beginning of January 2012 and therefore had partial activity data. In line with *Together for Short Lives* work on supporting the transition of young people into adulthood, one service had extended their age range from 25 to 30 years in 2011/12 and one service had previously reported provision up to 18 years and in 2011/12 also included their provision for young adults up to 35 years old.

A new categorisation of diagnosis was piloted in the 2011/12 data collection (based on a customised coding framework developed by Fraser *et al* (2011)). The categorisation was developed for children and young people who have been accepted for palliative care with diagnoses categorised into groups based on the main ICD10[9] codes (see Appendix C for full categorisation and guidance). As expected, not all providers could provide diagnosis by this classification.

The results presented below should be read with care, given that all hospice organisations did not respond. Responses are calculated on the number of children's hospice services responding to specific questions with non-responses noted alongside the reported data.

3.2. Type of children's hospice services provided

The types of support delivered by children's hospice services were wide-ranging (a glossary of terms can be found in Appendix B). All 43 services reported the provision of end-of-life care, family and sibling support and telephone advice and contact in at least one setting (from hospice, hospital, home and other setting options). Short breaks and emergency care were provided by 42 services (98%) and symptom management by 41 services (95%). Antenatal support was provided by 15 services (35%) and neonatal support by 33 (77%) (Fig 3.1).

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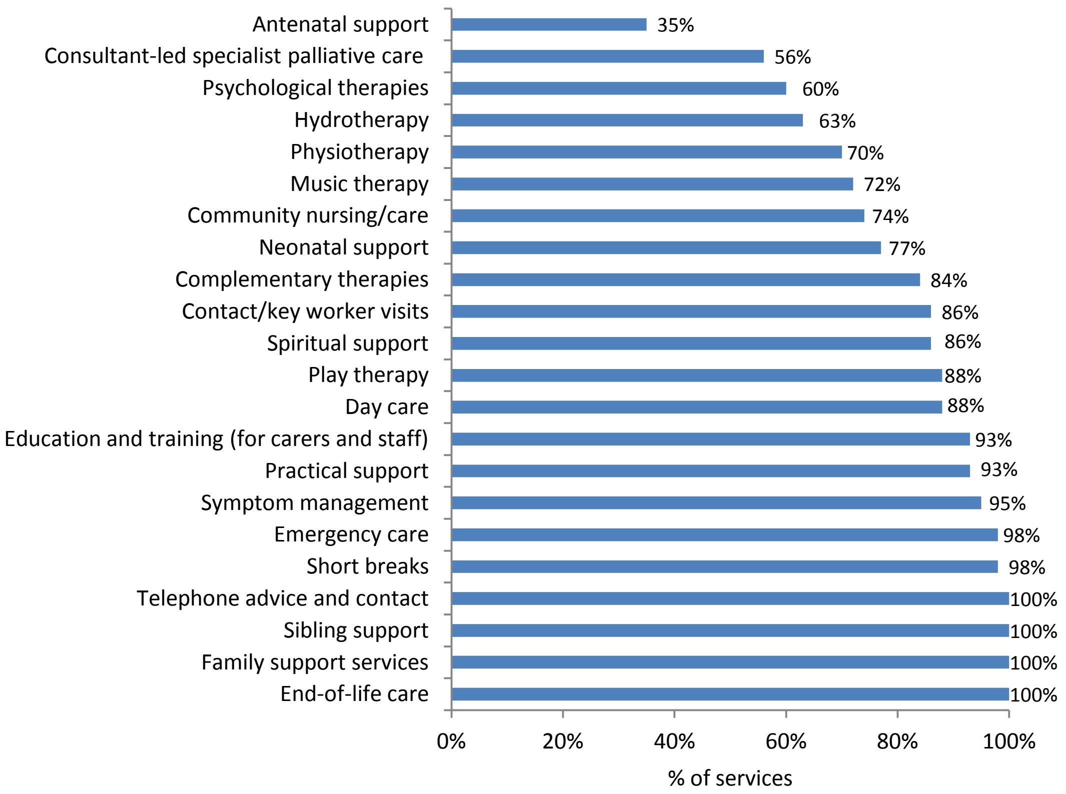
[9] International Statistical Classification of Diseases and Related Health Problems 10th Revision: http://apps.who.int/classifications/icd10/browse/2010/en

Fig 3.1: Types of children's hospice service provided (n=43)



39 services (91%) provided at least one type of care in a hospice setting (the four that did not were hospice at home/community teams). 41 services (95%) delivered at least one type of service in children and young people's homes and 27 services (63%) provided at least one type of service in hospitals. Many services were delivered in a combination of hospice, hospital and home settings with hospice and home being the most common combination. Service types delivered in other settings included day care and community nursing/care[10] in schools and the community; short breaks, family support and complementary therapies in the community; sibling support at youth groups, in school and the community; play and music therapy in schools and the community and contact/key worker visits in schools.

Table 3.1 presents the percentage of services that were only provided in either the hospice or at the child or young person's home. This applied to a range of services including 64% of short breaks being provided only in the hospice and 50% of community nursing/care only being provided in the child or young person's home. Additional settings in which services were delivered included day care in a hired centre (3%), hydrotherapy in a school (4%) and consultant-led specialist palliative care by telephone (13%).

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[10] Community nursing/care refers to hospice staff and the service they provide.

Table 3.1: Types of service only provided in one setting[11]

Type of service	Only hospice – number (and %) of services	Only home – number (and %) of services
End-of-life care	14 (33%)	4 (9%)
Family support services	6 (14%)	4 (9%)
Sibling support	8 (19%)	3 (7%)
Telephone advice and contact	19 (44%)	1 (2%)
Short breaks	27 (64%)	1 (2%)
Emergency care	15 (36%)	6 (14%)
Symptom management	11 (27%)	3 (7%)
Practical support	9 (23%)	3 (8%)
Education and training (for carers and staff)	18 (45%)	1 (3%)
Day care	13 (34%)	3 (8%)
Play therapy	15 (39%)	3 (8%)
Spiritual support	9 (24%)	2 (5%)
Contact/key worker visits	5 (14%)	7 (19%)
Complementary therapies	17 (47%)	3 (8%)
Neonatal support	11 (33%)	3 (9%)
Community nursing/care	1 (3%)	16 (50%)
Music therapy	10 (32%)	2 (6%)
Physiotherapy	20 (67%)	0
Hydrotherapy	26 (96%)	0
Psychological therapies	5 (19%)	0
Consultant-led specialist palliative care	8 (33%)	0
Antenatal support	2 (13%)	1 (7%)

All 43 children's hospice services provided bereavement support to children and families related to a child or young person who needed palliative care or used their services. 20 services (47%) also provided bereavement support to children and families who experienced bereavement in other circumstances.

All services provided post-bereavement support to parents and siblings and one-to-one bereavement work with parents (for example phone support and home visits). Pre-bereavement support for parents and siblings was provided by 42 services (98%) and memorial days for parents and siblings by 38 services (88%). A range of support was also provided for the extended family (Table 3.2)[12] as well as others including friends, school staff and other professionals. Some services also specified that they provided pre-bereavement support and counselling to the child with the condition. Other types of bereavement support specified included chaplaincy care, whole family work, structured peer support for bereaved parents and families, music therapy pre and post bereavement with siblings, bereavement packs for parents and the extended family, end of life planning and support in neonatal units, Paediatric Intensive Care Units and hospital wards.

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[11] The table is calculated and order based on the number of services reporting each type presented as percentages in Fig 3.1. All percentages have been rounded up or down to the nearest integer.

[12] The service that opened in January 2012 noted that their bereavement services would increase as the service develops.

Table 3.2: Types of bereavement support provided to families (n=43)

Type of bereavement support	Parents – number (and %) of services	Siblings - number (and %) of services	Extended family - number (and %) of services
Post-bereavement support	43 (100%)	43 (100%)	41 (95%)
Individual one-to-one bereavement work	43 (100%)	40 (93%)	35 (81%)
Pre-bereavement support	42 (98%)	42 (98%)	38 (88%)
Support and information about post mortem and funeral planning	42 (98%)	36 (84%)	35 (81%)
Referral to local bereavement services	39 (91%)	39 (91%)	33 (77%)
Hospice support post death (cool room and family support)	39 (91%)	39 (91%)	38 (88%)
Memorial days	38 (88%)	38 (88%)	37 (86%)
Bereavement support groups	36 (84%)	36 (84%)	25 (58%)
Counselling	25 (58%)	25 (58%)	23 (53%)
Drop-in sessions	24 (56%)	20 (47%)	17 (40%)
Befriending	16 (37%)	13 (30%)	11 (26%)
Play therapy	12 (28%)	36 (84%)	17 (40%)
Bereavement weekends	9 (21%)	19 (44%)	6 (14%)
E listening	4 (9%)	4 (9%)	3 (7%)

3.3. Support for technology dependent children and young people

All 43 services responded to a new question about support for technology dependent children and young people. All were able to support children and young people dependent on oxygen, 27 services (63%) could support essential ventilation (level 3) [13] and 14 (33%) were able to support children and young people dependent on renal dialysis (Table 3.3).

Table 3.3: Types of technological support provided (n=43)

Type of technology	Number (and %) of services
Oxygen	43 (100%)
Tracheostomy	42 (98%)
Supportive ventilation (Level 1/High level of need - can be discontinued for up to 24 hours without clinical harm)	41 (95%)
Enteral Nutrition	41 (95%)
Stoma care	41 (95%)
Urinary catheter care and/or catheterization	40 (93%)
Monitoring technologies (e.g. blood sugar)	38 (88%)
Necessary ventilation (Level 2/Severe level of need - has respiratory drive and would survive accidental disconnection, but would be unwell)	36 (84%)
Supportive intermittent intravenous/Subcutaneous therapies (not nutrition)	35 (81%)
Total Parenteral Nutrition	34 (79%)
Essential continuous intravenous/Subcutaneous therapies (not nutrition)	30 (70%)
Essential ventilation (Level 3/Priority level of need - unable to breathe independently, disconnection would be fatal)	27 (63%)
Renal dialysis	14 (33%)

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[13] Ventilation levels of need are adapted from Department of Health (2010) *National Framework for Children and Young People's Continuing Care*, pp. 49-50.

3.4. Referrals and children and young people supported

This section presents the information on referrals and children and young people supported in the period 1st April 2011 to 31st March 2012. In the data inputting stage of the collection participants were asked to enter the total number of referrals accepted and children and young people supported in the period and also to breakdown these figures by diagnostic category, age, gender and ethnic origin. Data were provided to these questions by all 43 reporting services except for diagnostic categories which is explained below.

In the following tables, the referrals accepted figures are those children and young people accepted into the service in the data collection period. The children and young people supported figures include those accepted and also the children and young people accepted in a previous year who continued to receive support by the service in the data collection period[14].

43 children's hospice services received 2,316 referrals and accepted 1,731 in the period 1st April 2011 to 31st March 2012 (Table 3.4). During this period 7,638 children and young people with life-limiting conditions, including those supported by hospice at home or community outreach schemes, were supported. 23% of the children and young people supported were accepted into the service during the data collection period.

Table 3.4: Breakdown of referral activity[15]

Referral activity	Number of referrals
Referrals pending on 1st April 2011	280
Referrals received between 1st April 2011 and 31st March 2012	2,316
Referrals accepted between 1st April 2011 and 31st March 2012	1,731
Referrals declined or not taken up between 1st April 2011 and 31st March 2012	469
Referrals pending on 31st March 2012	391

3.4.1. Source of referrals received

43 services provided a breakdown of 2,288 referrals received by source[16]. 664 (29%) of these were from community children's nurses, 324 (14%) from consultants and 274 (12%) from family members (Fig 3.2). 385 (17%) referrals were from other sources and these included family support workers, various types of nurses, midwives, allied health professionals, other community teams, chaplains, family friends and portage workers.

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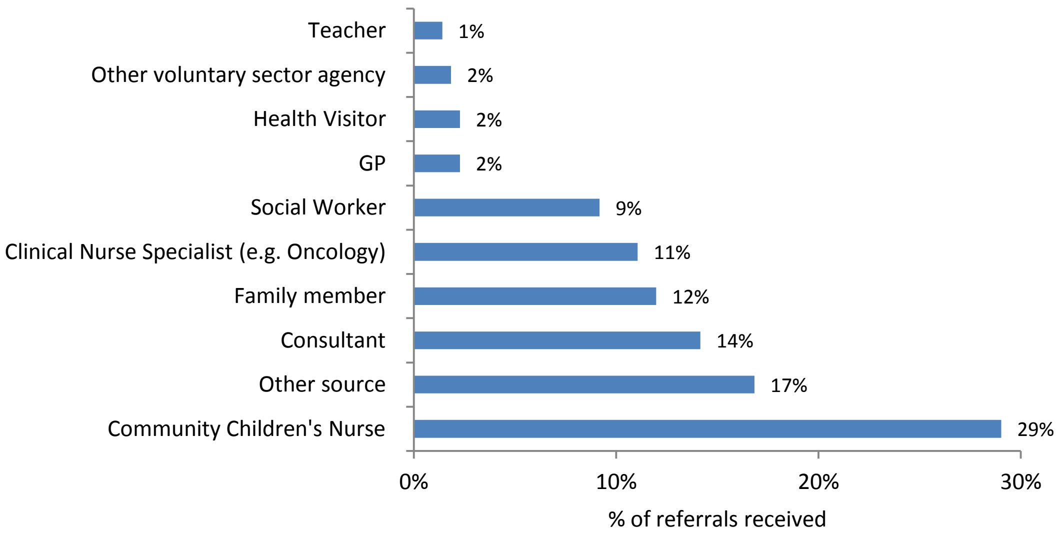
[14] The exception to this is the newborn to 28 day age band (neonatal) where although a referral may have been accepted the child did not then receive support by the service. As such, the number of referrals accepted for neonates was slightly higher than the number of children supported figure.

[15] The number of referrals pending at the start of the period, plus the number received, minus those accepted and declined/not taken up, should equal the number pending at the end of the period. Given this calculation the total pending at the end should be 396. However, one provider had incomplete referral records. The figures report the full data submitted.

[16] One service could only provide partial information to this question as they could not obtain information on some children and young people so percentages are calculated from 2,288 and not total referrals received (2,316).

Fig 3.2: Referrals received by source of referral (n=2,288)



3.4.2. Referrals accepted and children and young people supported by diagnostic categories

A new categorisation of diagnosis was piloted in the 2011/12 data collection (based on a customised coding framework developed by Fraser *et al* (2011)). The categorisation was developed for children and young people who have been accepted for palliative care with diagnoses categorised into groups based on the main ICD10[17] codes. Only ICD10 codes linked to life-limiting conditions were included (see Appendix C for full categorisation and guidance). The reason for moving to the new categorisation in this and future data collections is to achieve the aim of collecting information about diagnoses in a standardised way across children's hospices and to enable this information to be used alongside other data sources which use ICD10 codes to categorise conditions, such as Hospital Episode Statistics.

The new diagnostic categories question was introduced as an optional data item and 17 services (40%), provided by 12 organisations[18], were able to provide a breakdown using this categorisation (based on primary diagnosis). 188 (31%) accepted referrals were diagnosed in the neurology category, followed by 124 (21%) in congenital and 113 (19%) in oncology. There was a similar pattern for the children and young people supported in the period with 1,077 (43%) children and young people diagnosed in the neurology category, 481 (19%) in congenital and then 256 (10%) in oncology (Table 3.5). Given the low response and the piloting of the new categories the information should be read with care.

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[17] International Statistical Classification of Diseases and Related Health Problems 10th Revision: http://apps.who.int/classifications/icd10/browse/2010/en

[18] Two organisations provided three services each, one provided two services and the rest had one service per organisation.

Table 3.5: Referrals accepted and children and young people supported by diagnostic categories

Diagnostic category	Referrals accepted (n=603)	Children and young people supported (n=2,478)
Neurology	188 (31%)	1,077 (43%)
Congenital	124 (21%)	481 (19%)
Oncology	113 (19%)	256 (10%)
Other	56 (9%)	181 (7%)
Metabolic	36 (6%)	170 (7%)
Perinatal	31 (5%)	125 (5%)
Genitourinary	18 (3%)	37 (1%)
Circulatory	13 (2%)	30 (1%)
Haematology	9 (1%)	38 (2%)
Respiratory	9 (1%)	65 (3%)
Gastrointestinal	6 (1%)	18 (1%)

26 services (provided by 21 organisations[19]) were unable to provide the data by the new categorisation. The reasons for this are set out in Appendix C.

3.4.3. Referrals accepted and children and young people supported by age band

The 1,731 accepted referrals in the period included 15 pre-birth, 133 (8%) neonates, 795 (46%) children aged 29 days-4 years old and 465 (27%) aged 5-11 years. Information on 7,632 children and young people supported in the period[20] included 127 (2%) neonates, 1,755 (23%) 29 days-4 year olds and 2,626 (34%) 5-11 year olds. Young people over 16 year olds accounted for 7% of the referrals accepted and 23% of those supported in the period (Table 3.6).

Table 3.6: Referrals accepted and children and young people supported by age band[21]

Age bands	Referrals accepted (n=1,731)	Children and young people supported (n=7,632)
Pre-birth	15 (1%)	N/A
Newborn to 28 days	133 (8%)	127 (2%)
29 days-4 years	795 (46%)	1,755 (23%)
5-11 years	465 (27%)	2,626 (34%)
12-15 years	202 (12%)	1,362 (18%)
16-18 years	87 (5%)	927 (12%)
19-21 years	23 (1%)	468 (6%)
22-31+ years	11 (1%)	367 (5%)

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[19] Two organisations provided three services each, one provided two services and the rest had one service per organisation.

[20] This figure is six less than the total children and young people supported due to a change in reporting the number of pre-births.

[21] Upper age bands have been grouped together to avoid small numbers being reported.

3.4.4. Referrals accepted and children and young people supported by gender

Information was entered on the gender of the referrals accepted and children and young people supported by all 43 reporting services. 57% of both referrals accepted and children and young people supported in the period were male (Table 3.7).

Table 3.7: Referrals accepted and children and young people supported by gender

Gender	Referrals accepted (n=1,731)	Children and young people supported (n=7,638)
Male	983 (57%)	4,335 (57%)
Female	748 (43%)	3,303 (43%)

3.4.5. Referrals accepted and children and young people supported by ethnic origin

All 43 services entered information on the ethnic origin of their accepted referrals and the children and young people supported using the Office for National Statistics 2011 Census classification. For reporting purposes the ethnic origin groups are presented at the aggregate level to avoid reporting small numbers in some groups (see appendix D for full categorisation). 59% of referrals accepted and 62% of children and young people supported in the period were in the White category. 21% of referrals accepted and 22% of the children and young people supported were reported in the not stated category. Some services used the not stated category because they did not collect information on the ethnic origin of children and young people (Table 3.8).

Table 3.8: Referrals accepted and children and young people supported by ethnic origin

Ethnic origin	Referrals accepted (n=1,731)	Children and young people supported (n=7,638)
White	1,025 (59%)	4719 (62%)
Not stated	361 (21%)	1681 (22%)
Asian/Asian British	213 (12%)	718 (9%)
Black/African/Caribbean/Black British	55 (3%)	246 (3%)
Mixed/multiple ethnic groups	60 (3%)	208 (3%)
Other ethnic group	17 (1%)	66 (1%)

3.5. Families supported

Table 3.9 summarises the information entered for the number of families and siblings supported in the period 1st April 2011 to 31st March 2012. 43 services reported supporting 9,930 families (including bereaved families). 3,176 bereaved families were supported[22]. Each family was counted once regardless of the number of life-limited children and young people, parents or siblings in the family.

40 services collected information on the number of siblings they had supported in the period[23]. 8,862 individual siblings of both living children and those bereaved were supported by these

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[22] One organisation noted in the data checking that their figure for bereaved families included families supported over a number of years through annual remembrance days and anniversary cards. These families would be supported within each reporting period.

[23] One service only recorded the number of bereaved siblings supported (31). One service did not provide support to siblings and another did not provide structured sibling support so did not have comprehensive data to report.

services. 41 services provided information on the number of bereaved siblings supported and 2,586 were supported in the period.

Table 3.9: Number of families supported

Families supported	Number of families and siblings supported	Number of services reporting
Families supported (including bereaved families)	9,930	43
Bereaved families supported	3,176	43
Siblings supported (including bereaved siblings)	8,862	40
Bereaved siblings supported	2,586	41

3.6. Provision for young people and transition arrangements

There is a growing focus on making sure that young people with palliative care needs have a positive experience of transition from child to adult services (Marie Curie Cancer Care and the Transition Partnership, 2012). 40 services responded to a question asking for the upper age limit beyond which young people with life-limiting conditions are normally discharged from their service. This ranged from 18 to 35 years. 37 out of 43 services (86%) had staff trained to work with young people and 14 services[24] (33%) reported a separate wing or building for young people.

25 services (58%)[25] reported that separate adult services were provided by their organisation and 21 of these (84%) had internal arrangements for ensuring an effective transition for young people to these services with 16 (76%) ensuring young people preparing to transfer had a key worker[26] to provide ongoing support. Of those only providing services for children and young people[27], twelve (out of 17 responding – 71%)[28] had arrangements for ensuring an effective transition of young people from their service to adult services outside of their organisation and eight (67%) provided a key worker for the transfer to adult services. Five services (out of 11 responding - 45%) prevented young people from moving on if appropriate adult care services could not be identified for them.[29]

3.7. Number of deaths

All 43 children's hospice services reported a total number of 701 deaths in hospice care in the period 1st April 2011 to 31st March 2012, representing 9% of children and young people supported. The location for over half of the deaths of children and young people were either in the home (33%) or in a hospice (21%) (Fig 3.3).

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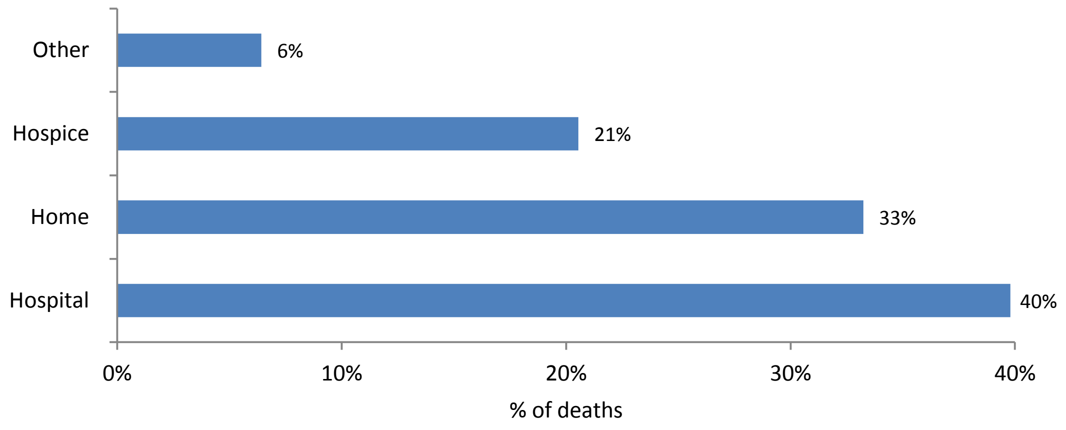
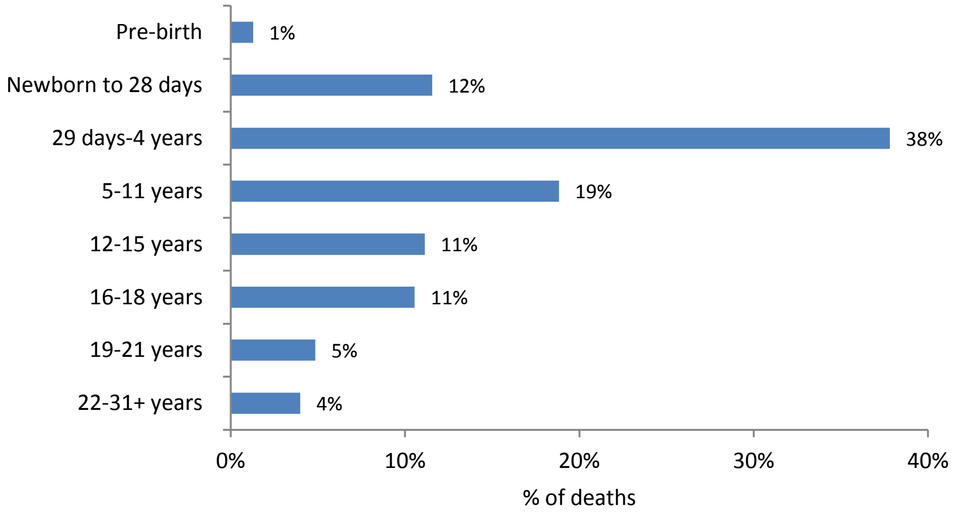
[24] Three services were provided by the same organisation. Not all services in the same organisation had the same arrangements in place.
[25] This included one organisation reporting three services. Not all services within the same organisation provided adult services.
[26] See Appendix B for key worker definition.
[27] 18 services provided by 12 organisations.
[28] One service did not answer the follow up questions about transition arrangements to adult services outside the organisation so the calculation is based on the total number of responding services.
[29] One service that reported arrangements in place did not answer this follow up question and the calculation is based on the total number of responding services.

Fig 3.3: Percentage of deaths by location of death (n=701)



All 43 services reported on 701 deaths by age band. 265 (38%) of these were 29 days-4 year olds, 132 (19%) were 5-11 year olds and nine deaths (1%) were recorded for pre-births. 20% of deaths reported were of young people aged 16 and over (Fig 3.4).

Fig 3.4: Percentage of deaths by age bands (n=701) [30]



3.8. Direct care team staff

Children's hospice services were asked to report the whole time equivalent (WTE) direct care team staff in post as of 31st January 2012 by staff group and by ethnic origin. 43 services reported a total WTE of 1,632. Nurses as a professional group made up 51% of the workforce (830 WTE), NVQ qualified healthcare workers made up 22% (365 WTE) and medical staff accounted for 1% (21 WTE) of the direct care team workforce (Table 3.10). The ratio of children and young people supported to

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[30] Upper age bands have been combined to avoid the reporting of low numbers.

WTE direct care team staff was 4.7. Three organisations employed a nurse consultant for paediatric palliative care[31].

Table 3.10: WTE direct care team staff by staff group (n=1,632)[32]

Staff group	Number (and %) of WTE
Registered Sick Children's Nurse/Registered Nurse (Child)	488 (30%)
NVQ qualified healthcare worker	365 (22%)
Dual qualified nurse[33]	180 (11%)
Other staff	140 (9%)
Nursery Nurse	103 (6%)
Registered General Nurse	63 (4%)
Registered Nurse Learning Disabilities	51 (3%)
Play Specialist	46 (3%)
Social Worker	45 (3%)
Nurse (unspecified/other)[34]	42 (3%)
Physiotherapist	27 (2%)
Medical staff	21 (1%)
Counsellor	20 (1%)
Youth Worker	12 (0.7%)
Teacher	8 (0.5%)
Occupational therapist	8 (0.5%)
Complementary therapist	7 (0.4%)
Registered Nurse Mental Health	6 (0.3%)
Psychologist	1 (0.05%)

Of the 1,632 WTE direct care team staff, 1,114 (68%) were in the White ethnic origin category and the ethnic origin of 471 WTE staff (29%) was reported as not stated (Table 3.11). Some services did not record ethnic origin information and used the not stated category.

Table 3.11: WTE direct care team staff by ethnic origin (n=1,632)

Ethnic origin	Number (and %) of WTE
White	1,114 (68%)
Not stated	471 (29%)
Asian/Asian British	19 (1%)
Black/African/Caribbean/Black British	14 (1%)
Mixed/multiple ethnic groups	11 (1%)
Other ethnic group	3 (0.2%)

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[31] One of these organisations provided three services and the nurse consultant was available in all three services.

[32] Figures have been rounded up or down to the nearest integer. Percentages have been rounded up or down to the nearest integer unless under 1% where one decimal place is included.

[33] For example, Registered Sick Children's Nurse and Registered General Nurse.

[34] This category was introduced in 2011/12 collection as one service did not have nursing data in the categories used in the collection. This service reported all of their 32.3 WTE nursing staff in this category in 2011/12 and two other services also entered data in it.

3.8.1. Medical cover

Services were asked specific questions about the types of medical cover in place. The following information is presented at organisation level. Some organisations with more than one service noted in their sign off report that they had charity-wide medical cover and reporting at the organisation level avoids potential double counting. However, it should also be noted that some organisations with more than one service did not report medical cover in every service and not all services responded to these questions so the information below should be read with caution.

At least one service in 22 organisations (67%) reported one or more type of medical cover from the options below. Specifically:

- Seventeen organisations employed a GP with a palliative care interest
- Eight organisations employed a paediatric palliative care consultant
- Seven organisations employed an adult palliative care consultant
- Five organisations employed an 'other' type of children's palliative doctor
- Four organisations employed other consultants.

3.9. Interagency working

All 43 services reported working with other agencies and professionals in delivering hospice care to children, young people and families. There were high levels of interagency working reported including all services working with community children's nursing teams and schools (including special schools) and 42 services (98%) working with paediatric oncology outreach nurse specialists and local authority children's services (Table 3.12). Other agencies or professionals specifically noted included adult providers, other voluntary sector organisations, PCTs, district general and specialist tertiary hospitals, allied health professionals, advocacy services, churches, Diana Teams and Macmillan Nurses.

Table 3.12: Interagency working (n=43)

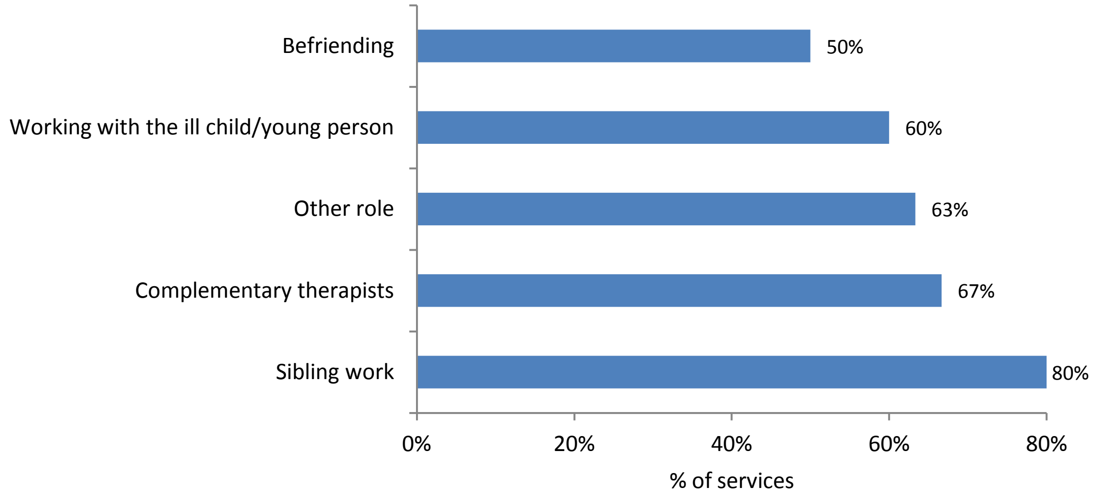
Agency or professional	**Number (and %) of services**
Community children's nursing team	43 (100%)
Schools (including special schools)	43 (100%)
Paediatric oncology outreach nurse specialist	42 (98%)
Local authority children's services	42 (98%)
Hospital ITU	39 (91%)
Community palliative care team	37 (86%)
Neonatal unit	37 (86%)
Short break facilities	33 (77%)
Consultant-led specialist palliative care team	30 (70%)
Carers support organisation	28 (65%)
Continuing care/complex needs nursing service for children and young people	22 (51%)

3.10. Volunteers involved in direct care

31 out of 43 services (72%) involved volunteers in providing direct care to children, young people and families and 27 (87%) of these had a volunteer manager or co-ordinator. The total headcount reported for volunteers involved in direct care was 1,722 ranging from 3 to 278. 30 services provided

information on the roles undertaken by volunteers. In 24 services (80%) volunteers worked with siblings, in 20 services (67%) they provided complementary therapy and in 18 (60%) worked with the ill child or young person (Fig 3.5). Other roles specified included therapeutic services, counselling, day care and support at group sessions.

Fig 3.5: Roles undertaken by volunteers (n=30)



3.11. Safeguarding arrangements

41 out of 43 services (95%) reported a named lead for safeguarding and systems in place to ensure safeguarding issues were reported regularly to the Hospice Board[35]. 19 services (44%)[36] were represented on the Local Safeguarding Children's Board (LSCB), 17 were not (40%)[37] and seven (16%)[38] answered that the question was not applicable[39].

3.12. User participation and feedback

All 43 services responded to a question about the ways in which parents, carers, children and young people were involved in various aspects of the design, implementation, delivery and evaluation of children's hospices services. Parents and carers were involved by more services than children and young people. The most common forms of participation for all users were feedback and evaluation of the service, forums and service design (Table 3.13). Other forms of participation specified included siblings involved in planning outings and events, young people consulted on manual handling developments, parents and carers involved in clinical governance assessments and care agreements, service evaluation forms and a comments/suggestions box at meetings and events.

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[35] Two services provided by the same organisation answered not applicable for all safeguarding questions. This might be due to having alternative safeguarding arrangements in place to those specifically asked about.

[36] Provided by 14 organisations including two with three services and one with two services.

[37] Provided by 15 organisations including one with three services.

[38] Provided by four organisation including one with three services and one with two services.

[39] LSCBs apply to England and Wales and other multiagency boards may be in place in other countries in the UK: http://www.nspcc.org.uk/Inform/research/questions/child_protection_system_wdf76008.pdf

Table 3.13: User participation and feedback (n=43)

Type of user participation	Children – number (and %) of services	Young people – number (and %) of services	Parents/Carers – number (and %) of services
Feedback and evaluation	38 (88%)	39 (91%)	43 (100%)
Child/youth/parental forums	16 (37%)	27 (63%)	37 (86%)
Service design	28 (65%)	35 (81%)	35 (81%)
Staff training	2 (5%)	10 (23%)	26 (60%)
Management committee/ Board of Directors	0	3 (7%)	20 (47%)
Delivery of service (e.g. peer support/young volunteers)	12 (28%)	18 (42%)	15 (35%)
Financial decision making	0	2 (5%)	13 (30%)
Recruitment of staff	2 (5%)	9 (21%)	11 (26%)
Other	1 (2%)	2 (5%)	1 (2%)

4. Comparable data for children's hospice services 2010/11 and 2011/12

4.1. Response rates and data issues

The following section reports comparable activity and staff data based on the 41 services that can be compared across 2010/11 and 2011/12 (32 organisations with six providing more than one service). Not all services were able to provide information to some questions and where this is the case the response rates are noted with the data presented. Please note the following information will not be the same as the 2011/12 totals reported in section 3.1 or in the 2010/11 national report as only those organisations that are comparable in the two years are reported here[40]. Please also note that inferences are not drawn from this data to all children's hospice organisations in the UK. Specific changes that have been taken into account when compiling the comparable data include:

- Exclusion of one organisation from 2010/11 as they did not complete the exercise in 2011/12
- The one new service for 2011/12 has been excluded
- One organisation has been excluded as they completed the exercise for up to 18 years in 2010/11 and for their whole service, up to 35 years, in 2011/12 and confirmed that their information is not comparable
- One organisation reported their transition unit in a separate questionnaire in 2010/11 and completed information for the whole organisation in one questionnaire in 2011/12. Information from the two 2010/11 questionnaires has been combined to make one service in this reporting
- Two organisations merged and completed one questionnaire for the whole service in 2011/12. The data from the two separate 2010/11 questionnaires has been combined and included in the comparisons following agreement with the organisation's lead
- One organisation extended their upper age range from 25 to 30 years in 2011/12 and is included.

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[40] A summary of data reported from 2004/05 to 2010/11 was provided in the 2010/11 data mapping report (Durham University Mapping Unit with Children's Hospices UK, 2011). This showed an overall increase in both the number of children and young people supported and the number of hospice services since 2004/05. However, due to different data sources and variations in the number of hospice services reporting, the information was not directly comparable year-on-year and should be read with care.

Data checks were carried out on 2010/11 and 2011/12 comparable activity and staff data and organisations were contacted if there was a significant increase or decrease in the figures between the years. All organisations that were contacted with checks responded to either confirm the data as correct, with many providing reasons for the change, or to amend their data. During the data checking a number of participants noted that they were not the person who had completed the data collection in 2010/11 and sometimes the previous person had left the organisation. On occasion the figures that had been entered in the 2010/11 data collection were identified as being incorrect but amendments could only be made to 2011/12 data. Given these changes and considerations the data should be read with care and compared with caution.

4.2. Children's hospice service activity and staff summary for 2010/11 and 2011/12

Table 4.1 presents the totals reported for key activity and staff data for the 41 comparable services. There were increases in the reported number of referrals received and accepted and children and families supported (including bereaved families) between 2010/11 to 2011/12 as well as the WTE direct care team. However, the ratio of children and young people supported to WTE direct care team staff did not change (4.8). While increases were reported in the number of referrals received and children and young people supported between 2010/11 and 2011/12, there was also 4% decrease reported in the number of deaths in hospice care from 697 in 2010/11 to 666 in 2011/12. This represents 10% and 9% of children and young people supported respectively. A number of services during the data checks confirmed increases in their caseload and their staff as well as some confirming decreases[41].

Table 4.1: Activity and direct care team summary 2010/11 and 2011/12 (n=41)

Activity and staff summary	**2010/11**	**2011/12**	**% change**
Referrals received	1,913	2,147	12%
Referrals accepted	1,491	1, 630	9%
Children and young people supported	6,823	7,357	8%
Families supported (including bereaved families)	8,871	9,522	7%
Deaths	697	666	-4%
Direct care team staff (WTE) [42]	1,422	1,535	8%
Children and young people supported to WTE direct care team staff	4.8	4.8	0%

Table 4.2 presents information that not all 41 comparable services could provide. This was because some organisations did not collect the number of bereaved families and siblings supported. The number of services comparable in the years has been included in the table as this varies for the different data items. Increases were reported in the number of bereaved families and the number of siblings supported but the number of bereaved siblings supported decreased[43].

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[41] Two services confirming increases in caseload and WTE staff had increased their beds (including the service that extended its upper age). One service had increased its WTE staff as the hospice was now open 24/7. Two services had been new in 2010/11 and in 2011/12 one had taken on more children and the other had the capacity to respond to increased end of life referrals. One service confirmed significant increases in the number of referrals and children, young people and families supported mainly as a result of NICU pathways being implemented and the embedding of a regional symptom management team. Their WTE staff had not increased due to more efficient use of existing staff resource and prioritising care but they were expanding their teams to meet the increased demand. One service confirming a decrease in WTE staff in 2011/12 was under their establishment and using bank staff. The referrals received by one service had reduced as they had worked to minimise inappropriate referrals.

[42] Figures have been rounded up or down to the nearest integer.

[43] One service noted that it had increased involvement with siblings in 2011/12 and that they supported some families with four or five siblings. One service confirmed a reduction in siblings supported but felt they needed to do some internal work on recording sibling support more consistently.

Table 4.2: Siblings supported and bereaved families and siblings 2010/11 and 2011/12

Families supported	2010/11	2011/12	Number of comparable services	% change
Bereaved families supported	2,873	2,947	40	3%
Siblings supported	7,646	7,873	33	3%
Bereaved siblings supported	2,592	2,286	34	-12%

4.3. Comparable activity data 2010/11 and 2011/12

Table 4.3 reports the source of the referrals received in 2010/11 and 2011/12 for the 41 services[44]. There was little change in the source of referrals between the two years. There were small decreases in the proportions of referrals received from Community Children's Nurses, consultants and health visitors and slight increases in the proportion received from family members, other voluntary sector agencies and other sources.

Table 4.3: Source of referrals 2010/11 and 2011/12

Source of referral	2010/11 (n=1,913)	2011/12 (n=2,119)
Community Children's Nurse	638 (33%)	639 (30%)
Other source	246 (13%)	336 (16%)
Consultant	290 (15%)	291(14%)
Family member	190 (10%)	248 (12%)
Clinical Nurse Specialist (e.g. Oncology)	188 (10%)	234 (11%)
Social Worker	193 (10%)	203 (10%)
GP	48 (3%)	52 (2%)
Health Visitor	80 (4%)	52 (2%)
Other voluntary sector agency	25 (1%)	35 (2%)
Teacher	15 (1%)	29 (1%)

41 services provided a breakdown of children and young people supported by ethnic origin (Table 4.4). There was a reduction in the percentage recorded in the not stated category from 23% in 2010/11 to 21% in 2011/12 but very little change in the ethnic origin of children and young people supported between 2010/11 and 2011/12, with an increase from 9% to 10% in the Asian/Asian British category.

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[44] 2010/11 data is a percentage of total referrals received for 41 services (1,913) and 2011/12 data is a percentage of 2,119 referrals received as one organisation had incomplete information on the source of referral.

Table 4.4: Children and young people supported by ethnic origin 2010/11 and 2011/12

Ethnic origin	2010/11 (n=6,823)	2011/12 (n=7,357)
White	4,205 (62%)	4,607 (63%)
Not stated	1,559 (23%)	1,526 (21%)
Asian/Asian British	601 (9%)	710 (10%)
Black/African/Caribbean/Black British	206 (3%)	244 (3%)
Mixed/multiple ethnic groups	199 (3%)	204 (3%)
Other ethnic group	53 (1%)	66 (1%)

Only 36 services could be used in comparison for the children and young people supported by gender and age bands between 2010/11 and 2011/12 as some services were unable to provide the information in the way it was asked for in 2010/11. There was consistency in the percentage of males and females supported by the 36 comparable services with 57% being male and 43% female in both years. There was also consistency over the two years in the ages of children and young people supported including young people aged 16 and over supported by services (Table 4.5).

Table 4.5: Children and young people supported by age bands 2010/11 and 2011/12[45]

Age bands	2010/11 (n=5,925)	2011/12 (n=6,371)
Newborn to 28 days	30 (1%)	49 (1%)
29 days-4 years	1,438 (24%)	1,487 (23%)
5-11 years	2,056 (35%)	2,271 (36%)
12-15 years	1,151 (19%)	1,173 (18%)
16-18 years	712 (12%)	793 (12%)
19-21 years	362 (6%)	381 (6%)
22-31+ years	176 (3%)	217 (3%)

A reduction in the number of deaths in hospice care was reported by 41 services from 697 in 2010/11 to 666 in 2011/12. Table 4.6 shows there was little change in the location of deaths with a 1% increase in the number of deaths at home. Over half of the deaths were outside of a hospital setting with home and hospice settings accounting for 53% and 54% of deaths respectively. 41% were in a hospital in both years.

Table 4.6: Location of deaths 2010/11 and 2011/12

Location of death	2010/11 (n=697)	2011/12 (n=666)
Hospital	289 (41%)	271 (41%)
Home	232 (33%)	225 (34%)
Hospice	141 (20%)	132 (20%)
Other location	35 (5%)	38 (6%)

4.4. Comparable direct care team staff 2010/11 and 2011/12

There was an increase in the total WTE of direct care team staff reported by 41 services from 1,422 WTE in 2010/11 to 1,535 WTE in 2011/12 (8%)[46]. Nursing numbers increased from a total of 736

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[45] Upper age groups have been grouped together to avoid small numbers being reported.

WTE to 778 (6%) but there was a slight decrease in this group as a proportion of the total workforce from 51% to 50%. Care should be taken when interpreting the nursing information as some services used the unspecified/other nurse category introduced in 2011/12 and this will impact on being able to compare the types of nurses between the two years[47]. There was an increase in the number and proportion of NVQ qualified healthcare workers from 302 WTE (21%) in 2010/11 to 351 WTE (23%) in 2011/12 but very few other changes in the staff groups between the two years (Table 4.7).

Table 4.7: WTE direct care team staff 2010/11 and 2011/12

Staff group	2010/11 number (and %) of WTE (n=1,422)	2011/12 number (and %) of WTE (n=1,535)
Registered Sick Children's Nurses/ Registered Nurse (Child)	454 (32%)	468 (30%)
NVQ qualified healthcare worker	302 (21%)	351 (23%)
Dual qualified nurse[48]	180 (13%)	170 (11%)
Other staff	131 (9%)	137 (9%)
Nursery Nurse	88 (6%)	88 (6%)
Registered General Nurse	53 (4%)	46 (3%)
Registered Nurse Learning Disabilities	43 (3%)	46 (3%)
Play Specialist	33 (2%)	45 (3%)
Social Worker	40 (3%)	43 (3%)
Physiotherapist	24 (2%)	26 (2%)
Medical staff	19 (1%)	18 (1%)
Counsellor	16 (1%)	17 (1%)
Youth Worker	8 (1%)	12 (0.8%)
Complementary therapist	13 (1%)	7 (0.4%)
Teacher	7 (0.5%)	7 (0.4%)
Occupational therapist	6 (0.4%)	7 (0.4%)
Registered Nurse Mental Health	6 (0.4%)	6 (0.4%)
Psychologist	1 (0.07%)	1 (0.05%)
Nurse (unspecified/other)	N/A	42 (3%)

5. Other third sector children's palliative care providers feasibility study

5.1. Response rates and data issues

Eleven other third sector children's palliative care providers, offering services similar to children's hospices were invited to participate in the data collection in 2011/12 to test the feasibility of including the wider sector in the data collection. Three providers completed questionnaires on ten services. It should be noted that eight of the services were provided by one organisation. One other provider only partially completed the questionnaire and their data is not included in this report. As this was a feasibility study a limited amount of information is reported and the figures should be read with the small number of participating organisations in mind.

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[46] See footnote 41 for the context of some of the staff changes. Figures have been rounded up or down to the nearest integer. Percentages have been rounded up or down to the nearest integer unless under 1% where one decimal place is included.

[47] This category was introduced in 2011/12 collection as one service did not have nursing data in the categories used in the collection. This service reported all of their 32 WTE nursing staff in this category in 2011/12 and two other services also entered data in it..

[48] For example, Registered Sick Children's Nurse and Registered General Nurse.

5.2. Activity and direct care team summary

Table 5.1 summarises the information provided by ten services on their activity for the period 1st April 2011 to 31st March 2012. 415 referrals were received and 403 accepted. 1,410 children and young people were supported and 1,415 families (including bereaved families). 29% of children and young people supported had been accepted into the service during the data collection period. There were 84 WTE direct care team staff, of which 23 WTE (27%) were nurses and 49 WTE (58%) were family support workers.

Table 5.1: Activity and direct care team summary (n=10)

Activity and staff summary	**Number**
Referrals received	415
Referrals accepted	403
Children and young people supported	1,410
Families supported (including bereaved families)	1,415
Bereaved families	162
Deaths	60
Direct care team staff (WTE)	84

In addition, eight services provided information on the siblings they had supported in the period. This was 1,681 siblings, including 220 bereaved siblings. Of the two services that did not report this information one did not collect data on siblings and one did not support siblings.

5.3. Example of potential comparison between children's hospice services and other third sector children's palliative care services

Table 5.2 is an example of the potential comparisons that can be made between the types of provider to explore similarities and differences within the sectors. It compares the proportions for the diagnostic categories reported by children's hospice services in 2011/12 (from section 3) with those of other third sector children's palliative care providers. Given the data issues previously outlined this information should be read and interpreted with care.

All ten other third sector children's palliative care services were able to breakdown the referrals accepted and children and young people supported by the new diagnostic categorisation. Table 5.2 shows the proportions of children and young people with different diagnostic categories supported by the two types of organisation. The main differences were 41% of children and young people supported by other third sector children's palliative care providers were in the oncology category and 10% were in this category in children's hospices. 43% of children and young people in children's hospices were in the neurology category and 9% were in this category in other third sector children's palliative care providers.

Table 5.2: Children and young people supported by diagnostic categories

Diagnostic category	Other third sector children's palliative care providers (n=1,410)	Children's hospices (n=2,478)
Oncology	572 (41%)	256 (10%)
Congenital	188 (13%)	481 (19%)
Other	163 (12%)	181 (7%)
Neurology	131 (9%)	1,077 (43%)
Circulatory	88 (6%)	30 (1%)
Respiratory	65 (5%)	65 (3%)
Metabolic	63 (4%)	170 (7%)
Haematology	55 (4%)	38 (2%)
Perinatal	36 (3%)	125 (5%)
Genitourinary	26 (2%)	37 (1%)
Gastrointestinal	23 (2%)	18 (1%)

6. Conclusions and Recommendations

Conclusions

The data collection was undertaken as a collaborative exercise combining *Together for Short Lives* knowledge and networks and the Durham University team's experience in data collection. It achieved excellent response rates thanks to the engagement of providers. The project expanded on work previously undertaken to further establish a systematic approach to collecting and presenting information on children's third sector palliative care services.

Robust data is required to understand children's palliative care provision and the users of services. The data collected through this project may be used as a source of information to raise questions around gaps in provision, overlaps in delivery and equity of access to services at local, regional and national levels. It can therefore contribute to the further development and improvement of services for life-limited children and young people and their families. In evaluating the 2011/12 exercise, 81% of respondents[49] agreed that the information collected was a useful source for their organisation and 83%[50] agreed it was a useful source of national information. We also hope that this will be of interest to the current palliative care funding review pilot work being carried out in England. To ease the process of data collection, and to maximise its value, we make the following recommendations.

Recommendations

- A consistent and embedded annual collection will support the comparison of data year-on-year in order to build an understanding of changes within the sector. We believe that the collection should continue as an annual exercise, monitoring important trends in children's hospice provision including:
  - the ages of children and young people using the services, particularly in relation to issues of transition into adult life
  - the recording of the ethnic origin of children and young people and
  - the number of deaths outside of hospitals.

- The collection of data from other children's third sector palliative care providers could be rolled out to other *Together for Short Lives* members, based on the positive responses to the feasibility study this year.

- The content of future collections should be informed by discussion with *Together for Short Lives*, care providers, commissioners, national leads, local networks and professionals with an interest in data about children's palliative care, to ensure the continued relevance of the data. Stakeholders should be able to access and use the data collected.

- Data collection categories should continue to be aligned with other collections to allow for comparison and triangulation of data. In particular, the classification of diagnostic categories piloted this year should be used again, allowing for comparison of hospice data with data about palliative care in the NHS through Hospital Episode Statistics.

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[49] 17 out of 21 organisations.
[50] 19 out of 23 organisations.

- There should be close liaison with providers about the collection of consistent data items to ensure robustness of data and reduce future burden.

- Providers should have as much advance notice as possible of the questions that will be asked to enable them to prepare and collate information.

- This collection of service provision and activity data could be combined with the *Together for Short Lives* finance data collection to create an integrated service and finance collection. This would mean conducting the collection on a different scheduled timescale but would ease the administrative burden on participating organisations and provide a broader basis for comparison between organisations.

- The Palliative Care Funding Review Team is invited to utilise the report data to assist them with the children's pilot site data collections and the development of the national Tariff.

Appendix A: List of children’s hospices in the UK and participating other third sector children’s palliative care providers

Thirty-three children and young people’s hospice organisations, out of thirty-five in the UK, participated in 2011/12 data collection. Two organisations did not have the capacity to participate at the time of the data collection. Questionnaires were completed on 43 services (six organisations provided more than one service as outlined below).

Hospice organisations	Number of questionnaires completed (services mapped)
Acorns Children's Hospice Trust	3
Alexander Devine Children’s Hospice	0
Bluebell Wood Hospice	0
Butterwick Hospice Care	1
Chestnut Tree House Children's Hospice	1
Children's Hospice Association Scotland (CHAS)	2
Children's Hospice South West (CHSW)	3
Claire House Children's Hospice	1
Demelza Hospice Care for Children	3
Derian House Children's Hospice	1
East Anglia Children's Hospices (EACH)	3
Eden Valley Hospice	1
EllenorLions Hospices	1
Francis House Children's Hospice	1
Haven House Children's Hospice	1
Havens Christian Hospice	1
Helen and Douglas House	1
Hope House Children's Hospices	2
Iain Rennie Hospice at Home	1
Jessie May Trust	1
Julia's House	1
Keech Hospice Care	1
Martin House Children's Hospice	1
Naomi House Children's Hospice	1
Noah's Ark Children's Hospice	1
Northern Ireland Hospice	1
Rainbows Hospice for Children and Young People	1
Richard House Children's Hospice	1
Shooting Star CHASE Children's Hospice	1
St Andrew's Hospice	1
St Oswald's Hospice	1
The Donna Louise Children's Hospice Trust	1
The West Yorkshire Forget Me Not Trust	1
Trinity Hospice	1
Ty Hafan	1

Participating other third sector children’s palliative care providers

Eleven other third sector children’s palliative care providers, providing similar services to children’s hospices, were invited to participate in the 2011/12 data collection. Three completed the exercise and in addition, The Children’s Trust partially completed a questionnaire but the information entered is not included in this report.

Other third sector children’s palliative care providers	Number of questionnaires completed (services mapped)
James Hopkins Trust	1
Rainbows Trust	8
Zoe’s Place	1

Appendix B: Glossary of terms

Antenatal support
This is support provided to parents before the birth of their child where the child is known to have a life-limiting or life-threatening condition.

Community nursing/care
Community nursing provides nursing and supportive care often at home and in other community settings. They often act as a key worker and liaise with other agencies.

Complementary therapies
This includes a range of complementary therapies designed to offer physical comfort, emotional support and relief from symptoms.

Contact/key worker visits
Key working or care co-ordination is a service, involving two or more agencies, that provides disabled children and young people and their families with a system whereby services from different agencies are co-ordinated. It encompasses individual tailoring of services based on assessment of need, inter-agency collaboration at strategic and practice levels and a named key worker for the child and their family. Families with disabled children should only have a key worker if they want one. (Care Co-ordination Network UK, 2006) (The Association for Children's Palliative Care (2009) *Children's palliative care definitions*)

Day care
Provision of daytime training, supervision, recreation, and often medical services for children and young people with life-limiting conditions.

Education and training (for carers and staff)
This is the delivery of education and training programmes/sessions to carers and also professionals within and outside of the children's hospice service.

Emergency care
This is provision of services for children and young people who need medical advice, diagnosis and/or treatment quickly and unexpectedly.

End-of-life care
End-of-life care services are services to support those with advanced, progressive, incurable illness to live as well as possible until they die. These are services that enable the supportive and end-of-life care needs of both child/young person and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support. This is not confined to discrete specialist services but includes those services provided as an integral part of the practice of any health or social care professional in any setting. (The Association for Children's Palliative Care (2009) *Children's palliative care definitions*)

Family support services
This is support provided to the family of children with life-limiting or life-threatening conditions. It may include workshops and focus groups, individual work, support on an ad hoc basis and activity weekends/days.

Neonatal support
This is support provided for babies in the first 28 days of life who have a life-limiting or life-threatening condition.

Practical support
Practical support includes providing access to clinical equipment, financial grants, suitable housing and domestic help. (The Association for Children’s Palliative Care (2010) *The ACT Charter*)

Short breaks
Short break care has three main functions: To provide the child or young person with an opportunity to enjoy social interaction and leisure facilities; To support the family in the care of their child in the home or an alternative community environment such as a children's hospice; To provide opportunities for siblings to have fun and receive support in their own right. Short breaks may offer the whole family an opportunity to be together and to be supported in the care of their child or it may offer care solely for the child or young person. (The Association for Children’s Palliative Care (2009) *Children’s palliative care definitions*)

Sibling support
This is the provision of support to the siblings of children with life-limiting or life-threatening conditions. This may include support groups, individual work, support on an ad hoc basis and activity weekends/days.

Symptom management
Symptom management is the management of common symptoms associated with life-limiting conditions. It is often used to refer to symptoms that are primarily physical, but in palliative care symptom management also includes attention to psychosocial and spiritual aspects of symptoms where appropriate. (The Association for Children’s Palliative Care (2009) *Children’s palliative care definitions*)

Telephone advice and contact
This is the provision of specialist telephone advice to the families of children and young people with life-limiting or life-threatening conditions.

Appendix C: New 2011/12 diagnostic categorisation

This categorisation is based on a customised coding framework developed by Fraser *et al* (2011).

Diagnostic category	**Guidance notes**
Oncology	**Examples:** Neuroblastoma; Astrocytoma; All Central Nervous System tumours (including benign). **Main ICD 10 Chapter:** C codes. **Additional ICD 10 codes:** D33; D43; D48.
Neurology	**Examples:** Muscular Dystrophy; Spinal Muscular Atrophy; Congenital myopathies. **Main ICD 10 Chapter:** G codes. **Additional ICD 10 codes:** A17; A18; F80.3; F84.2.
Haematology	**Examples:** Human immunodeficiency virus; Beta thalassaemia; Immunodeficiencies; Aplastic anaemia. **Main ICD 10 Chapter:** D codes. **Additional ICD 10 codes:** B20-24. **Excluded ICD 10 codes:** Any D codes for benign tumours should be in oncology category.
Congenital	**Examples:** Syndromes e.g. Cockayne; Chromosomal e.g. Edwards, Patau; Congenital Cardiac Disease. **Main ICD 10 Chapter:** Q codes.
Metabolic	**Examples:** Adrenoleucodystrophy; Nieman Pick; Gauchers; Proprionic Acidaemia. **Main ICD 10 Chapter:** E codes. **Excluded ICD 10 codes:** E84 Cystic Fibrosis goes in Respiratory.
Respiratory	**Examples:** Cystic Fibrosis; Fibrosing Alveolitis. **Main ICD 10 Chapter:** J codes. **Additional ICD 10 codes:** E84.
Circulatory	**Examples:** Primary Pulmonary Hypertension; Cardiomyopathy. **Main ICD 10 Chapter:** I codes. **Excluded ICD codes:** Any Q codes for congenital heart disease go in congenital.
Genitourinary	**Examples:** Acute Renal Failure; Chronic Renal Failure. **Main ICD 10 Chapter:** N codes.
Gastrointestinal	**Examples:** Liver failure; Cirrhosis of Liver; Vascular Intestinal Disease. **Main ICD 10 Chapter:** K codes.
Perinatal	**Examples:** Severe birth asphyxia; Congenital cytomegalovirus, Rubella, Toxoplasmosis Hypoxic Ischaemic Encephalopathy. **Main ICD 10 Chapter:** P codes.
Other	**Examples:** Failed organ transplant/rejection; Kearns Sayre. **Main ICD 10 Chapter:** H codes; M codes. **Additional ICD 10 codes:** T86.

21 organisations, providing 26 services, were unable to provide diagnostic information by the new categorisation. Feedback on reasons for not being able to provide this was given by 21 services:

- Do not currently use ICD10 or categorise diagnoses in this way (5 services)
- Information collected by ACT categories (7 services)
- Information collected by CHASE categories (2 services)
- Do not record category of diagnosis (1 service)
- Some children do not have a diagnosis and some have multiple diagnoses (1 service)
- We were not advised at the beginning of the reporting year that this would be required so it was not collected. We would have been able to collect this if known. We will be able to do this next year (3 services)
- Not yet moved to ICD10 categorisation. This is work in progress and will be available for the 2012/12 data collection (1 service)
- Difficulties obtaining accurate data off database. A new database is being installed this year (1 service).

Six services noted that they would be able to provide information by this categorisation in the 2012/13 data collection.

Appendix D: Ethnic origin classification

The classification used for the ethnic origin questions was the 2011 Office for National Statistics 2011 Census classification. The high level groupings were used for reporting the information combining the various categories used in data entry.

High level category for reporting	Categories used in data entry
White	White: English/Welsh/Scottish/Northern Irish/British
	White: Irish
	White: Gypsy or Irish Traveller
	White: Any other White background
Mixed/multiple ethnic groups	Mixed/multiple ethnic groups: White and Black Caribbean
	Mixed/multiple ethnic groups: White and Black African
	Mixed/multiple ethnic groups: White and Asian
	Mixed/multiple ethnic groups: Any other Mixed/multiple ethnic background
Asian/Asian British	Asian/Asian British: Indian
	Asian/Asian British: Pakistani
	Asian/Asian British: Chinese
	Asian/Asian British: Bangladeshi
	Asian/Asian British: Any other Asian background
Black/African/Caribbean/Black British	Black/African/Caribbean/Black British: Caribbean
	Black/African/Caribbean/Black British: African
	Black/African/Caribbean/Black British: Any other Black/African/Caribbean background
Other ethnic group	Other ethnic group: Arab
	Other ethnic groups
Not stated	Not stated

Appendix E: Participant evaluation of the data collection

This section presents the results of the evaluation questionnaire used as part of the data collection. This was accessible to all organisations when they signed off their service questionnaire(s). One questionnaire was provided for each organisation. This evaluation feedback in structured in three sections following the main report:

1. 2011/12 responses by children's hospice organisations
2. 2010/11 and 2011/12 children's hospice organisation comparable responses
3. 2011/12 other third sector children's palliative care organisation feasibility study responses.

1. 2011/12 responses by children's hospice organisations

In 2011/12, leads from 23 children's hospice organisations completed the evaluation questionnaire but response rates varied for different sets of questions and the reported figures include the number of organisations returning data on the specific topics reported.

Data inputting process

22 out of 23 organisations (96%) agreed that the website was easy to use and the layout of the questionnaire was straightforward. 19 organisations (83%) agreed that inputting data into the questionnaire was straightforward and 18 organisations (78%) that the onscreen guidance and definitions helped with completing the exercise.

Other people assisted the Lead with the data collection in 20 of the 23 organisations (87%). The number of other people involved ranged from one to nine with an average of four people (based on 19 responses). The estimated amount of time in hours taken to complete the exercise across 20 organisations ranged from 2 to 35 with an average time of 13 hours.

The email helpdesk was used by 7 out of 23 respondents (30%) and all agreed that the advice given was useful. Eleven respondents who did not use the email service said this was because they did not need assistance. The other respondent who provided an answer to this said that they needed to speak to someone as the data requested was not clear.

Respondents were asked to describe what additional guidance and support would help them in completing the exercise. Responses included:

- The diagnostic category breakdown isn't straightforward use of ICD10, as a non medical person collating these stats or even writing a report to summarise. More detail is required to provide accuracy
- Better guidance around definitions of how to include siblings supported. Does that mean receiving actual therapeutic support or those may attend fun days and social group activities?
- The pages could be smaller so all of the categories can be seen at the same time
- When you hit a radio dial, the screen is refreshed and you are taken to the top of the page again. This is a bit confusing when you are not familiar with the 'form'.
- Each section (ethnicity, diagnostic categories etc.) should be on a separate sheet so you do not have to scroll all the time when 'correcting'.
- Totals should be displayed before you leave the screen so you pick up any anomalies as you go along rather than having to go back and forth.

Questionnaire content

16 out of 21 organisations (76%) did not find any questions unclear and 10 organisations (48%) did not have difficulties providing information in the format requested. Specifically, 16 out of 23 organisations (70%) agreed that the activity information was easy to collect in the format requested. Difficulties in providing the information included different categorisations in internal databases to those in questionnaire, in particular the new diagnostic categorisation, and difficulties with extracting information from their own database including a lack of training.

A number of respondents also commented in the data checking process that their organisation was having a new database installed and that it would be easier to complete the data collection once this was in place.

Questions were also asked to ascertain the way in which the activity and staffing data had been collected for the exercise. The activity data was mainly collected through a combination of routinely collected data and specific collection of the information requested for the exercise (52%). Staff data was collected specifically for the exercise in six organisations (26%) (Table 1.1).

Table 1.1: The way in which the required data was collected (n=23)

Way of collecting data	Activity data	Staff data
Some data was routinely collected, other aspects collected specifically for this exercise	52%	39%
Existing information systems that routinely collect information within the organisation	35%	35%
All data was collected specifically for the mapping exercise	13%	26%

Data checking and sign off

The data checking process was found to be useful in 20 out of 23 organisations (87%) and 21 (91%) agreed that the sign off process was easy to follow. Table 1.2 reports the types of data checks that participants undertook with most checking information at the collecting, inputting and reporting stages.

Table 1.2: Types of data checks undertaken (n=23)

Type of data check	% of organisations
The information was checked at collecting, inputting and reporting stages	91%
Used the data summary/sign off report	74%
Staffing levels/ratios checks	57%
Data checked against other sources	39%

Use of data

17 of 21 responding organisations (81%) agreed that the data would be a useful source of information for their organisation. 19 of 23 organisations (83%) agreed that the data would be a useful source of information nationally and 13 (56%) would use the tools developed from the exercise. Ways in which participants thought it would be useful to present the data included:

- A national picture
- Comparison of own organisation's data with data from other children's hospices
- Data presented at full team meeting.

2. 2010 and 2011/12 comparable children's hospice organisation responses

The comparable results to the evaluation questionnaire for children's hospice organisations in 2010/11 and 2011/12 are summarised below. Please note that feedback to the helpdesk indicated that in a number of organisations the person completing the exercise in 2011/12 was different to that of 2010/11 and the results should be read with this in mind.

The following is based on the results from 16 comparable organisations in 2010/11 and 2011/12. Response rates to different questions varied and where fewer organisations were comparable this is noted next to the data presented:

- There was a decrease by one organisation in those who agreed that the website was easy to use from 16 organisations (100%) in 2010/11 to 15 (94%) in 2011/12. In both years 15 out of 16 organisations (94%) agreed that the layout of the questionnaire was straightforward.

- Two more organisations agreed in 2011/12 that inputting data into the questionnaire was straightforward (from 11 organisations (69%) in 2010/11 to 13 (81%) in 2011/12). Fewer organisations agreed that the onscreen guidance and definitions had helped in 2011/12 (13 organisations - 81%) than in 2010/11 (15 organisations - 94%) although agreement levels were still very high.

- Other people assisted with the data collection in 15 organisations (94%) in 2010/11 and 16 (100%) in 2011/12 with an average of 4 people helping in both years. For 13 comparable organisations the estimated amount of time taken to complete the exercise decreased from 14 hours in 2010/11 to 11 hours in 2011/12.

- Only two respondents used the email helpdesk in 2011/12 compared to five in 2010/11. All that used this found the advice given useful.

- There was an increase in organisations that had difficulties reporting information in the format requested, from three (19%) in 2010/11 to seven (44%) in 2011/12. This was in relation to both the categories and their own databases. In both years, ten organisations (63%) agreed that the activity information was easy to collect in the format requested and only three organisations (19%) found any questions unclear.

- As tables 2.1 and 2.2 show there was an increase in organisations using existing information systems to provide the activity data for the collection but a decrease in using this method for the staff data. One quarter in both years specifically collected staff data for this data collection.

Table 2.1: The way in which activity data was collected in 2010/11 and 2011/12 (n=16)

Way of collecting data	2010/11	2011/12
Some data was routinely collected, other aspects collected specifically for this exercise	56%	50%
Existing information systems that routinely collect information within the organisation	25%	44%
All data was collected specifically for the mapping exercise	13%	6%
Other	6%	0%

Table 2.2: The way in which staff data was collected in 2010/11 and 2011/12 (n=16)

Way of collecting data	2010/11	2011/12
Existing information systems that routinely collect information within the organisation	44%	38%
Some data was routinely collected, other aspects collected specifically for this exercise	25%	38%
All data was collected specifically for the mapping exercise	25%	25%
Other	6%	0%

- There was an increase in organisations using the data sign off/summary report to check the data from nine organisations (56%) in 2010/11 to 12 (75%) in 2011/12. There was also an increase in organisations checking the data at all stages of the data collection process with 11 (69%) doing this in 2010/11 and 14 (88%) in 2011/12. Eight organisations in both years checked staff levels/ratios and in 2010/11 nine checked the information entered against other sources and seven checked this in 2011/12.

- Of 15 comparable organisations, 12 (80%) in 2010/11 and 13 (87%) in 2011/12 agreed that the data checking process was useful and 14 (93%) in both years agreed that the sign off process was easy to follow.

- Of 15 comparable organisations, 14 (93%) in 2010/11 and 12 (80%) in 2011/12 agreed that the information would be a useful source for their organisation. 13 organisations (87%) in 2010/11 and 12 (80%) in 2011/12 agreed the information would be a useful source nationally. Of 14 comparable organisations, seven (50%) in both years agreed they would use the tools developed from the exercise.

3. 2011/12 other third sector children's palliative care organisation feasibility study responses

The three other third sector organisations that completed the exercise responded to the evaluation questionnaire. They all agreed that the website was easy to use and the layout of the questionnaire was straightforward. Two agreed that inputting data into the questionnaire was straightforward and one disagreed. Two agreed that the onscreen guidance and definitions helped with completing the exercise and one had no opinion on this.

Only one organisation had help completing the exercise. This was from the Deputy Director of Care. None of them used the email helpdesk and two noted that this was because support was not required.

Two organisations answered a question asking about the estimated time it had taken to complete the exercise. One responded 10 hours and the other 15 hours with the majority of the time being used to collect the information rather than inputting or checking.

Two organisations did not have difficulties providing the information in the format requested. The one that did noted that this was because the categories in their database were different to those used in the exercise. None found any questions unclear. The activity data in one organisation was taken from existing information systems but this was not easy to collect in the requested format. In the other two organisations some of the data was routinely collected but other aspects were collected specifically for this data collection and they found the activity information easy to collect in the format requested. Existing information systems were used for staffing data in two organisations and the other one used both existing systems and had to collect some information specifically.

All three organisations checked the information they reported at the collecting, inputting and reporting stages. One used the data summary/sign off report and checked staffing levels and ratios and one checked the data entered against other sources. All agreed that the sign off process was easy to follow and that the data checking process was useful.

All three organisations agreed that the data would be a useful source of information for their organisation and that they would use the tools developed from the exercise. Two agreed that the data would be a useful source of information nationally with the other having no opinion on this.

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