Introduction

The briefing provided as part of the commissioning process for this piece of work was:

To undertake work to understand who accesses children’s palliative care, their needs and current state of children’s hospice provision across the UK by:

I. Undertaking a Delphi survey to reach consensus on who the children and young people accessing hospice support are and the scope of their needs;

II. Undertaking a literature review;

III. Development of report.

The following report outlines the findings of a Delphi survey undertaken in December 2017-January 2018 of hospices in the UK and palliative care service providers.

A literature review on palliative care and hospice service provision in the UK was also carried out, the findings of which are summarised below.

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The National Children’s Bureau (NCB) was commissioned by Hospice UK and Together for Short Lives to undertake research aimed at understanding who accesses children’s palliative care, their needs and the current state of children’s hospice provision across the UK. In December 2017 – January 2018 a Delphi survey was carried out of hospice providers and other palliative care services to elicit information on children and families accessing support and the scope of their needs.

There is a dearth of literature pertaining specifically to children and young people’s experience of palliative care services, possibly because of researchers’ ethical concerns around working with children, young people and their parents at such a sensitive and distressing time.

Much of the UK-based literature in this field relates to one of the following themes: documenting the illness experience, focussing on a discrete experience of children or their parents; decision-making about care and treatment, with a particular focus on the issue of patient ‘choice’ of service delivery; pain and symptom management; delivery of palliative care services, in particular the commissioning process and challenges for the workforce; the funding of services; and the experience in local settings.

Much of the literature, whilst acknowledging the ethical sensitivities of carrying out research with such vulnerable families, calls for more intentional participatory work around including the voices of children, young people and their parents/carers.

Profile of children and young people accessing hospice and palliative care services

Survey respondents were asked to provide information on the profile of the children and young people using their services.

One third of providers who responded to the survey indicated that they support children and young people up to the age of 18. Smaller numbers of responses indicated other age ranges and specifically mentioned providing support during the transition stage from children to adult services.

Almost all respondents highlighted the diverse nature of the support provided depending on the needs of the young person, especially emphasising the relationship between the length of support and the diagnostic stage at which the referral is made.

Most respondents referred to accepting referrals of children and young people (and their wider family members) who have ‘life-limiting, ‘life-shortening’ or ‘life-threatening’ conditions as defined by the ACT/RCPCH.

Some respondents indicated that some of the young people they support may not be referred with a specific clinical diagnostic condition but may present with symptoms indicating that they would meet one of the four categories as outlined by the ACT/RCPCH.

1 A form of two-stage survey which collects data from a set of questions in an initial survey and then summarises that set of data to inform the questioning in a second round of survey questions. A total of 18 responses were received to round one of the survey and seven to round two from hospices and other palliative care providers in England and Wales

2 A more detailed review of the literature is available as part of the full version of this report.

3 Formerly the ACT, now Together for Short Lives
Nature of service provided

The diversity of the services offered matches the understanding of hospice provision as outlined by Hospice UK and Together for Short Lives which emphasise the heterogeneity of providers. 4, 5

The aspect of service provision which almost all responding services shared was the offer of support to parents/carers, siblings and wider family members.

More than half of respondents also provide respite care of different lengths of stay (usually between 17-25 days), counselling and specialist play/play therapy. Nearly half of services offer support to bereaved children/young people and music therapy.

Approximately a third of services provide symptom management support, art therapy and support provided via outreach or at a place of choice.

Smaller numbers of providers responding to the survey report offering more specialist services, such as: chaplaincy/spiritual care; complementary therapies; specialist nursing support; hydrotherapy; physiotherapy; interactive sensory room; crisis care; long-term ventilation support; legal advice; peritoneal dialysis respite; aromatherapy support; dad and male carers support group; parallel planning; anticipatory care planning; support to teachers and other school staff; school projects where children can meet adult patients who are living with a palliative condition. 6

Referrals, access and exclusion criteria

The majority of responses indicated that referrals can be made by a healthcare professional (HCP) or by a parent/carer. HCPs mentioned as the principal sources of referral included: paediatric wards of acute hospitals; tertiary centres such as Great Ormond Street Hospital; social workers; school nurses; General Practitioners (GPs); children’s community nurses; nursery nurses; clinical nurse specialists; paediatricians; health visitors; foetal medicine; neonatal services and allied health professionals.

A number of exclusion criteria were mentioned by organisations, including deaths from: sudden accidental death including road traffic accidents; suicide; unlawful killing; stillbirth; miscarriage; brief sudden onset of illness which resulted in the death of a child. One respondent referred to exclusion criteria around pre-existing significant mental health or learning disabilities needs.

Challenges

The need to address possible misconceptions around the nature of hospice services and palliative care in general was highlighted across the breadth of responses and in particular the resulting impact of late referrals and an observation that potentially-eligible children and young people are not accessing services to which they would be entitled.

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6 However, as the total number of respondents was only 18, these figures are presented as indicative of the profile of this group of 18 only and should not be interpreted as applying to the provision of hospice services or palliative care more generally.
However, whilst recognising that greater numbers of children and young people could potentially be encouraged to access palliative care services, conversely, capacity was also highlighted as an issue by a number of respondents. Particular gaps were emphasised in relation to community care and the challenges of providing round-the-clock support.

Capacity was considered by most respondents as an ongoing challenge with the combined potential jeopardies of: the difficulties of recruiting and retaining specialist, qualified and trained staff; the resulting pressures on the voluntary sector of funding cuts within the NHS; and the potential impact of Britain leaving the European Union on staffing levels.

Challenges around capturing meaningful impact data when supporting this particular group of children and young people were highlighted along with the sensitivities of data capture. Transition to adult services was a reported area of concern, particularly the challenges of having experienced staff to work with those who present with complex healthcare conditions, diagnosed in childhood and continuing into adulthood.

In relation to the commissioning of services, the variation in available services across regions was a reported issue, with particular gaps identified in some rural areas, the differences in catchment support areas for children and adults being a concern and the need highlighted for greater cooperation in the planning of services across areas.

One respondent referred to the perception that hospice services are still thought of as a ‘nice to have’ rather than an essential support service to children, young people and their families. Another discussed how models to support service need to be able to adapt to the circumstances of each family:

‘The larger part of living with a life-limiting condition, death, loss and grief takes place away from the children’s hospice. If we want to make the maximum difference to people’s lives the focus must shift towards improving their life experiences for the 94% of the time and for those families that do not access hospice services. The demand for hospice services cannot be met in the future through this traditional model as funding will not keep pace with demand and thus a new approach to the model of care is required.’

A more detailed write-up of the findings of this research is available in the fuller report which accompanies this executive summary.
The commissioned form of data collection for this piece of work was a Delphi survey. Shariff (2015) outlines how the Delphi form of surveying has been a methodological choice for more than 50 years. Named after a Greek oracle at Delphi who made use of a network of expert informers, the Delphi approach is ‘a systematic process which aims to: gather information on a specific issue, involves a group of experts that reach consensus through iterative rounds with the use of questionnaires, whose opinions are anonymous, expert panelists do not meet physically and maybe [sic] geographically dispersed’ (Shariff, 2015).

The Delphi approach collects data from a set of questions in an initial survey and then summarises that set of data to inform the questioning in a second survey. Participants are therefore invited to respond to the findings of the first round of questioning as a method of validating (or not) the initial set of findings. Shariff draws on literature which recommends a sample size of a minimum of 10 and a maximum of 50. Unlike other surveys, Delphi studies do not call for representativeness of the sample size for statistical purposes.

Two rounds of survey questions were distributed. A total of 18 responses were received to round one in December 2017; seven complete and useable responses were received to round two in January 2018. In this study, the second round of the survey was sent to the entire initial sample, not only those who responded to the first round. Of the seven responses to round two, five were from ‘new’ respondents and two were from respondents who had also participated in the first round.

Both surveys were structured to elicit mainly qualitative responses. Responses were therefore coded thematically to both rounds. The coding framework generated by responses to round one was used to inform the development of the questions used for the second survey.

The first survey elicited the following information: the name of the individual respondent, the organisation represented, and the UK nation where the organisation is based. Four main questions were then asked to which the respondent was invited to provide written responses in open text boxes:

- **Who are the children and young people who access your service?**
  Consider their characteristics like: their age ranges; genders; typical frequency and patterns of accessing services; length of engagement with your service.

- **What support does your organisation provide?**
  Consider any and all: functions; services; facilities; support, including to the wider family.

- **How do children, young people and families access your service?**
  Consider any and all: referral processes and pathways from other organisations or services; thresholds to access your service; eligibility criteria for your service; your service’s relationships to referring services/organisations.

- **What are the challenges facing your service and the possible development areas to address them?**
  Consider: capacity; workforce; children, young people and families who are not engaged with hospice services; changing prognosis and expected treatment pathways; transition.

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1 A smaller sample size than 10 would not generate enough data; a larger sample size than 50 is not thought to be cost efficient.
A rapid review of the available literature was carried out via University College London’s library services’ electronic search tool, ‘Explore’, which acts as a gateway service to a range of subscription-only and open access databases. Terms applied to the search included a combination of: hospice; palliative; child; children; youth; young; service; experience; funding; care. Literatures included for review were dated from 2000 onwards, were in English language only and focussed only on UK contexts – both in terms of author institutional base and services studied.

In reference to palliative care research in general (as opposed to research pertaining specifically children and young people), Higginson (2015) draws upon research by Neuberger (2013) which expressed serious concerns about a lack of research in this field and underuse of existing research. In the context of palliative care services to children and young people, Cooley et al. (2000) document the ‘lack of research which enables practitioners to question their current practice’, citing possible ethical concerns on the part of any potential researchers in this field as a barrier to working with children, young people and their parents at such a sensitive and distressing time.

In the limited context of this report, a brief summary of the UK-relevant literature is provided below, organised by the following themes: documenting the experience of illness; decision-making about care and treatment; pain and symptom management; delivery of palliative care services; funding of services; and local settings.

### Documenting the illness experience

Outputs under this theme are usually focussed on a specific and discrete experience of children or their parents. Laddie et al. (2014) for example developed guidance for practice around the withdrawal of ventilator support outside the intensive care unit based on a retrospective 10-year case review of patients in intensive care whose parents had elected to withdraw ventilatory support in another setting. Tietze et al. (2012) reviewed the literature from 1980 – 2009 (61 publications) on sleep disturbance in children with multiple disabilities, calling for validated assessment tools for this group of children and young people. In a series of papers on post-traumatic stress disorder (PTSD) and myocardial infarction, Chung and colleagues (Chung et al., 2007; Chung et al., 2008 and Jones et al., 2007) through their application of Posttraumatic Stress (PTSD) diagnostic instruments with more than 100 patients, report that patients who underwent certain medical interventions and procedures such as bypass surgery and angioplasty tended to report more PTSD symptoms.

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[2] For a more international focus, cf Together for Short Lives published Synopsis (2018) – an international digest of children’s palliative care research abstracts. Issued twice a year, this is a collection of 470 abstracts, as opposed to a review of the literature but provides a useful catalogue by which to explore possible avenues of literature. Abstracts are presented according to seven different themes: clinical and ethical decision-making; education, research and professional issues; epidemiology and pathology; outcomes and instruments; pain and symptom assessment and relief; providing services for children and families; psychosocial and family issues. https://www.togetherforshortlives.org.uk/wp-content/uploads/2017/12/ProRes_SynopsisVol1No10_Jul18.pdf Last accessed October 2018.

[3] Some of this literature are research outputs related to work programmes by the Louis Dundas Centre for Children’s Palliative Care. Founded in March 2010 and hosted by Great Ormond Street Hospital (GOSH) and the Institute of Child Health (ICH) at University College London (UCL), the centre was established to conduct research into the experiences of children and young people with life-limiting conditions and life-threatening illnesses and their families. The research carried out under the auspices of this institute has drawn on the clinical experience of staff at both institutions, outputs of which aim to have policy and practice applications.
An open-access doctoral thesis (Sayers, 2014) in clinical psychology at the University of Leicester explored mothers’ experiences of hospice provision in the care of their child(ren). In this qualitative study, eight participants were recruited via a convenience sampling method across two hospice sites in one region of the UK. Conducted via analysis of diaries and through interviews, this thesis offers a powerful and nuanced account of the experience of mothers whose children are patients of hospices.

**Decision-making about care and treatment**

The Louis Dundas Centre’s research programme sought to embed the voices of children and young people to form an ‘evidence base for how some of medicine’s most challenging decisions are made’. Research carried out under this strand aimed to answer the questions: what are the significant steps in the decision-making process?; what should the child or young person’s role be in that process?; how are parents and children best served by clinicians and other healthcare professionals as they consider the options for care and treatment? In one of the outputs under this strand, Bluebond-Langner, Belasco & Demesquita Wander (2010) outline considerations around involving children with life-threatening and life-limiting illnesses in decision-making regarding care and treatment and ‘suggests an approach to involving children that recognizes their abilities, vulnerabilities, and relationships with others while at the same time ensuring an ethical and meaningful role for children’.

A further study by Bluebond-Langner et al. (2013) undertook a systematic review of the literature around ‘preferred place of death for children and young people with life-limiting and life-threatening conditions’. Their review found that the assertion commonly cited that ‘home is the preferred place of death in the United Kingdom and elsewhere’ usually relies on data concerning adults and not evidence about children. Of the nine studies reviewed for the study, six referred to experiences of children who had died from cancer. The review calls for further data collection from parents, children and siblings.

Craig & Mancini (2013) explore the question of choice around place of death in neonatal palliative care, concluding that where choice is currently offered, the proportion of hospital deaths is significantly lower than national statistics suggest but that the high proportion of hospital deaths overall indicates that choices are not being offered (as opposed to being unavailable) to parents.

Dunbar, Carter and Brown (2018) explored parents’ perspectives and experiences of a hospice, to understand the barriers and/or facilitators to accessing a hospice, and to gain a better understanding of what characteristics parents wanted from hospice provision. The study found that finding a place where they belonged and felt at ‘home’ made the parental decision to accept help in caring for their child with a life-limiting condition more acceptable.

**Pain and symptom management**

Rajapaske, Liossi & Howard (2014) present evidence that supports the development of a ‘biopsychosocial concept’ of chronic pain, arguing that the experience of pain is shaped by a ‘complex interaction...’.

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of biological, psychological and social factors [...] rather than a straightforward reflection of the severity of disease or extent of tissue damage'. This paper outlines how the pain associated with different kinds of illnesses has a clinical impact upon a child’s sleep. Principles of pain management for frequently-encountered chronic pain problems are also discussed, namely: neuropathic pain, complex regional pain syndrome (CRPS), musculoskeletal pain, abdominal pain and headache.

**Delivery of palliative care services**

Craft and Killen (2007) undertook a review of children’s palliative care services in England, commissioned by the Department of Health which highlighted the lack of understanding of children’s palliative care services and a lack of clarity around who was responsible for leading the planning and development of services at national, regional and local levels. Also in 2007, the Department of Health commissioned ‘Better Care: Better Lives. Improving outcomes and experiences for children, young people and their families living with life-limiting and life-threatening conditions’. This documented a set of strategic goals around: collection of data; access to universal services; accountable leadership; choice and community services; better end-of-life care; commissioning; workforce planning and transition between children’s and adult services.

The Louis Dundas Centre looked to identify physical, social, psychological, economic or structural barriers to children and families receiving quality palliative care and what can be done to remove them. Twamley et al. (2013) conducted a cross-sectional survey of healthcare professionals (HCPs) in a paediatric tertiary care hospital in the UK to explore staff perceptions of barriers with the aim of developing interventions to increase patient access to palliative care services. Their research found an association in the understandings of HCPs between palliative care and death/dying. This kind of understanding was also reported in the responses to the survey carried out in the preparation of this report (discussed further below). Mancini, Kelly and Bluebond-Langner (2013) report on the elements of training needed to ensure a specialist workforce for the future in the delivery of services in the field of neonatal palliative care. Their analysis is structured through four lenses of knowledge, capacity, competency and confidence.

Patel, Coad & Murray (2012) refer to the Department of Health funded evaluation into the West Midlands Children and Young People’s Palliative Care services as the impetus for their literature review into communication barriers experienced by paediatric palliative care staff when interacting with children, young people and families. They report that the main communication barriers relate to: a perceived lack of staff knowledge about emotional support; the style in which staff conveyed diagnostic information; the constant change of professionals interacting with families and the lack of formal training and guidelines for staff to meet the needs of children and families with additional complex care needs.

Barnes (2013), via a review of the literature, explored issues of staff stress in the context of children’s hospices, particularly causes, effects and coping strategies, concluding that a poor relationship with the patient’s family as well as an inability to relieve distressing symptoms experienced by the child were common causes of staff stress. Teamwork, good communication and the ‘homelike’ atmosphere of the hospice environment were all cited as stress alleviators.

McConnell and Porter (2017) conducted a qualitative study (through in-depth interviews and focus groups), into the experiences of providing end-of-life care at a children’s hospice, by focussing on 40 members of staff of a care team within a children’s hospice in Northern England. Formerly the Department of Health, now the Department of Health and Social Care.
Ireland. Staff reported positive experiences in their work through the knowledge that they were ‘making a difference’ in the lives of children, young people and their families and took comfort in the experience of working within a team environment. Challenges were reported throughout the study around managing end-of-life symptoms and reducing distress for the patient and family members, communicating with families, managing their own grief and balancing complex end-of-life care with respite care. The study recommended better developed communication, knowledge exchange, peer support and learning networks between children’s hospices and hospital settings.

Hospice UK have published a guide to supporting hospice staff which includes a review of the impact of staff stress on the care provided to patients, the causes of stress in the workplace and possible action to be undertaken at the individual and the organisational level.

A 2018 systematic scoping review (Booth et al., 2018), whilst highlighting the ‘limited high quality research in aspects of care for infants, children and young people with life-limited conditions’, calls for researchers to include the views of children, young people and their families in determining research priorities. In the 24 studies which met the researchers’ inclusion criteria for review, 279 research questions or priority areas for research were identified (with a range of 4-82 across the sample and an average of 17 per study). The main research areas identified were: population (including access to services); measurement and assessment; service delivery and models of care; health and other interventions (including adherence); symptom management and control; emotional and psychological issues; participation and inclusion; communication and decision-making; other family needs and support; practices related to palliative and end-of-life care; bereavement; ethics; workforce; and funding. Many of these issues map on to those highlighted as part of the two-stage Delphi survey carried out for the purpose of this report.

Funding of services

The 2011 Palliative Care Funding Review identified a ‘stunning lack of data on the costs of palliative care in England’. The review outlined a per-patient funding mechanism for palliative care by creating an ‘NHS palliative care tariff’. Under the tariff model, the funding follows the patient with the level of funding available per patient being dependent on the stage of phase of illness (stable; deteriorating; unstable; dying) and age group (0-1yrs; 2-13yrs; 14-25yrs; >25yrs). Certain kinds of service cannot be funded via the tariff, namely: bereavement care (except for a pre-bereavement assessment), spiritual care, complementary therapies, support for carers and families, information and advice, respite care for adults, play therapy, and other similar interventions.

Gardiner, Ryan & Gott (2018) reviewed the literature around the costs of a palliative care approach in the UK and found that it was not possible to provide an aggregate cost of palliative care in the UK. Their review found that ‘it is notable that the costs of hospice care and informal care are often neglected in economic studies’.

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6 Hospice UK ‘Resilience: a framework supporting hospice staff to flourish in stressful times’

7 At the time of writing, the Palliative Medicine journal had issued a call for papers for a special issue on paediatric medicine, seeking contributions ‘from across many health care disciplines on the topic of care for seriously ill children and their families’.

Local settings

Billings and Jenkins (2011) were commissioned by Children’s Hospices across London (CHaL) learning and development group to set out a ‘learning and development strategy’ for children’s hospices across London which included an audit of policy and practice in London’s children’s hospices. This review focussed on training and evaluation rather than the support needs of children, young people and their families.

A 2015 audit of children’s palliative care services in the East Midlands makes reference to children’s outcome measures and provides suggestions for ‘ideal’ future models of care. It also highlights the lack of discharge planning pathways for children with complex needs and the problematic issues of available transportation for a deteriorating child or neonate to be able to leave hospital to have end of life care in their own home. The study also found that despite recommended quality standards, there were no identified lead nurses for paediatric palliative care in any of the hospitals in the area. There were also very few paediatric palliative care doctor sessions in the region and most areas did not have an identified lead doctor for children’s palliative care.

Hunt et al. (2013) conducted a study around life-limited children and their families in the West Midlands (also known as ‘The Big Study’) which combined quantitative and qualitative research with the aim of developing a better understanding of families’ met and unmet needs and proposed suggestions for how better care for children, young people and families may look like.

Maynard (2012) reported on the evaluation of a new specialist nursing service providing 24/7 symptom management for children with life-threatening and life-limiting conditions and their families, funded by the True Colours Trust and implemented by East Anglia Children’s Hospices. This evaluation developed a nursing Logic Model for a network approach to 24/7 care which (the study reported) demonstrated relationships between investments into the service and results of the evaluation. Critical success factors were having the right level of specialist and advanced nursing skills; formalised and funded on-call arrangements; anticipatory care planning; presence of written symptom management plans, access to good quality clinical supervision and making best use of evidence based practice derived from other disciplines and sectors.

Following this summary of the literature, in the following sections, the narrative turns to a summary of the survey findings (round one, followed by round two).

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A total of 18 responses were received to the first round of the survey. All responses to round one were received in December 2017. Following the protocol of the Delphi method of survey distribution, a second survey was then developed based on the first round responses.

Second round responses were received in January 2018. Respondents to both rounds of the survey were assured of anonymity. Responding individuals and the organisations they represent have therefore not been named in this report. However, the following information is provided by way of a brief summary of the profile of responding organisations.

**Round one respondents**

Of the 18 responses received, 12 were based in England, five in Wales and one which covered locations in England and Wales. Twelve of the 18 respondents were from hospice services.

The other responses were received from (as self-described): a palliative care team, a clinical network for children’s palliative care, a palliative care network, a local health board, a teaching health board and a support service.

**Round two respondents**

Of the seven responses received, all seven were from hospice services, six of which were based in England and one covering locations in England and Wales.

The responses to the survey have been thematically analysed by type of question.
Who are the children and young people who access your service? Consider their characteristics like: their age ranges; genders; typical frequency and patterns of accessing services; length of engagement with your service.

Responses to the first question of (round one of) the survey can broadly be described as the profile of the children and young people (and wider family members) using the service (client group). When looking at the group of respondents as a whole, all responses indicated that they provide services to children and young people of both genders.

In terms of age ranges, different age ranges were cited. Not all responses referred to a specific age range. However, the table below outlines the age range of young people to whom services are offered when age ranges featured amongst responses.

Table 1: Age of those accessing services

<table>
<thead>
<tr>
<th>Age range (in years)</th>
<th>Number of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-16</td>
<td>1</td>
</tr>
<tr>
<td>0-18</td>
<td>6</td>
</tr>
<tr>
<td>0-19</td>
<td>3</td>
</tr>
<tr>
<td>0-24</td>
<td>1</td>
</tr>
<tr>
<td>0-25</td>
<td>2</td>
</tr>
<tr>
<td>0-18 + transition into adult services</td>
<td>1</td>
</tr>
<tr>
<td>0-20 (+ transition to 25)</td>
<td>1</td>
</tr>
<tr>
<td>24wks-25yrs</td>
<td>1</td>
</tr>
<tr>
<td>16-35 [end of life to 40 years]</td>
<td>1</td>
</tr>
</tbody>
</table>

Three respondents also referred to providing support for families who have experienced a life-limiting diagnosis in pregnancy.

Respondents referred to providing services to children and young people with ‘life-limiting’, ‘life-shortening’ or ‘life-threatening’ conditions. Some of the respondents work with children and young people who have been bereaved or will be bereaved in addition to working with children and young people who have a life-shortening condition themselves.

One respondent described how the nature of the service differs for those young people who have cancer compared with other conditions:

‘There is a 20/80 split between those who have cancer vs non-malignant conditions. Those with cancer tend to access regular services for shorter periods, typically 1-12 months.

Those with non-malignant conditions may access our regular services for many years, occasionally for the full 25 years [...] before referral on to adult services. The non-malignant group encompass a wide spectrum of diagnoses, some very unique and unclassified. Neonatal referrals tend to have intensive input for much shorter periods of time - hours to days or weeks, rather than months. All of these have ongoing bereavement support.

The mode in which children and young people die is unpredictable, because the range of conditions that cause death in childhood is extraordinarily wide. That heterogeneity makes it hard to predict in an individual child or young person what the mode of death will be, although there is some evidence that death can be heralded by deteriorating respiratory function, evolving bowel failure or worsening seizures.’

1 Please refer to the terminology definitions included as an appendix to this report.
One respondent stated that many of their children and young people don’t have a formal diagnosis at the point of entry into the service. Another responded that they manage a caseload of children with unspecified ‘complex ongoing health needs’, some of whom will have a ‘life-limited’ diagnosis and some of whom will be under the care of an oncology service. Another respondent stated that they provide services to young people who have ‘learning disabilities with significant cognitive impairment and full care needs’. In some cases, because of the genetic nature of conditions, multiple family members with the same condition will be supported.

Almost all respondents stressed how the service offered can be tailored to meet the heterogeneity of the needs of the children and young people accessing the services and their families.

For some services the length of engagement is varied and can range from a ‘one-off’ meeting with advice or signposting to attending a 6-week bereavement group or months of support focussed on an impending loss or learning to manage and live with a limiting illness. One respondent stated that each family is ‘typically engaged with [the service] for many years. Typically, children with life-limiting/life-shortening on the case load are seen either when having troubling symptoms or when they are dying.’

Another reported working with children from the point of diagnosis until death and then providing ongoing bereavement support for the family, in some cases for decades. Another response indicated that following the death of a child, post-bereavement support services can be offered to family members for up to two years before referring on to another service provider. Many organisations provide a support service to siblings of those with a life-limiting diagnosis. One organisation stated that for every child on their caseload, wider support is provided for between five-eight family members.

One respondent indicated that families of children on long-term ventilation provide ‘family stays’ of up to seven to nine months. Some organisations provide both day and overnight care, some for brief periods and others for more extended stays, depending on needs. Most respondents provide different kinds of support depending on where in his/her diagnostic journey the child is referred into the service, with some children accessing services for years and others being referred for end-of-life care.
What support does your organisation provide? Consider any and all: functions; services; facilities; support, including to the wider family.

Responses to this question were varied. The table below outlines the main types of support which were common across many responses. Some more detail is then provided on the kinds of more specialist or niche support offered by some providers. The types of support described in the table below have been collected under what are considered to be common terms referring to the type of support offered. These may not match exactly the language used by each individual support provider.

Table 2 (see right) outlines the kind of support offered by more than one responding organisation. The following kinds of support were also referred to by respondents, but in these cases were mentioned by only one responding organisation: family information service; emergency respite; benefits support; legal advice; peritoneal dialysis respite; special school clinic; aromatherapy support; dad and male carers support group; parallel planning; anticipatory care planning; support to teachers and other school staff; school projects where children can meet adult patients who are living with a palliative condition.

In terms of the respite care offered, most organisations mentioned stays of between 17-25 days (with one organisation offering a total of 48 nights per family spread over the course of one year). Some organisations specifically used the term psychosocial support as an umbrella term to describe the services they offer; others focussed on the person-centred nature of the support provided.

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12 It is of course possible that such services are offered by more than one organisation but that they did not feature amongst the responses provided.

<table>
<thead>
<tr>
<th>Type of service provided</th>
<th>Number of respondents who referred to offering services of this type</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care of wider family (including sibling support) pre and post bereavement</td>
<td>17</td>
</tr>
<tr>
<td>Hospice care</td>
<td>12</td>
</tr>
<tr>
<td>End of life care for children and young people</td>
<td>10</td>
</tr>
<tr>
<td>Short breaks/respite care</td>
<td>9</td>
</tr>
<tr>
<td>Counselling</td>
<td>9</td>
</tr>
<tr>
<td>Specialist play/play therapy</td>
<td>9</td>
</tr>
<tr>
<td>Care of bereaved children and young people</td>
<td>8</td>
</tr>
<tr>
<td>Music therapy</td>
<td>8</td>
</tr>
<tr>
<td>Service delivered via outreach or in choice of place</td>
<td>6</td>
</tr>
<tr>
<td>Symptom management</td>
<td>6</td>
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<tr>
<td>Art therapy</td>
<td>5</td>
</tr>
<tr>
<td>Specialist social work</td>
<td>5</td>
</tr>
<tr>
<td>Care of children and young people living with a palliative condition</td>
<td>4</td>
</tr>
<tr>
<td>Chaplaincy/spiritual care</td>
<td>4</td>
</tr>
<tr>
<td>Day care</td>
<td>4</td>
</tr>
<tr>
<td>Complementary therapy</td>
<td>4</td>
</tr>
<tr>
<td>Emotional health and wellbeing support</td>
<td>3</td>
</tr>
<tr>
<td>Specialist nursing support</td>
<td>3</td>
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<tr>
<td>Hydrotherapy</td>
<td>3</td>
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<tr>
<td>Accommodation for families</td>
<td>3</td>
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<tr>
<td>Transition to adult services</td>
<td>3</td>
</tr>
<tr>
<td>Physiotherapy</td>
<td>3</td>
</tr>
<tr>
<td>Crisis care</td>
<td>2</td>
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<tr>
<td>Interactive sensory room</td>
<td>2</td>
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<tr>
<td>Long-term ventilation support</td>
<td>2</td>
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<tr>
<td>Fun days</td>
<td>2</td>
</tr>
</tbody>
</table>
How do children, young people and families access your service? Consider any and all: referral processes and pathways from other organisations or services; thresholds to access your service; eligibility criteria for your service; your service’s relationships to referring services/organisations.

The majority of responses indicated that referrals can be made by a healthcare professional (HCP) or by a parent/carer. HCPs mentioned as the principal sources of referral included: paediatric wards of acute hospitals; tertiary centres such as Great Ormond Street Hospital; social workers; school nurses; General Practitioners (GPs); children’s community nurses; nursery nurses; clinical nurse specialists; paediatricians; health visitors; foetal medicine; neonatal services and allied health professionals.

Respondents made reference to different referral and exclusion criteria. A number of responses referred to weekly multidisciplinary meetings at which potential referrals are discussed and decisions are made.

Many organisations apply the four criteria around life-limiting or life-threatening conditions as developed by the Association for Children’s Palliative Care and the Royal College of Paediatrics and Child Health (ACT/RCPCH). A life-threatening condition is one in which medical intervention may prove successful but by its nature carries a substantial chance of mortality in childhood (ACT/RCPCH 2nd edition, 2003). A life-limiting condition is one for which there is currently no cure available and the likelihood is that the condition will lead to the child dying prematurely (Sutherland, Hearn, Baum & Elston, 1994). For those respondents who work with wider family members, the eligibility criteria is applied only to the child or young person.

ACT and the RCPCH (2003) suggest that there are four groups of condition:

1. Life-threatening conditions for which curative treatment may be feasible but can fail, where access to palliative care services may be necessary when treatment fails. Children in long term remission or following successful curative treatment are not included, e.g. cancer.

2. Conditions where premature death is inevitable, where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities, e.g. cystic fibrosis.

3. Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years, e.g. Battens disease, muscular dystrophy.

4. Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complication and likelihood of premature death, e.g. severe cerebral palsy.

A summary of a number of individual responses are provided below by way of illustrating how such criteria can differ depending on the individual service or local area.

**Example 1:** One respondent from a hospice setting stated that children and young people are initially referred to the whole hospice service and not individual elements of the service. New referrals are usually discussed at a weekly in-house multidisciplinary team meeting. Urgent referrals can be decided upon outside of the usual weekly meeting. This particular hospice accepts referrals of any child under the age of 19 years living in three local counties who has a life-limiting condition. Referrals for young people aged 17/18 years old who are not requiring end-of-life care will be considered by the
multi-disciplinary team based on individual need at the point of referral and the services required to meet those needs. This service has developed a paediatric referral criteria checklist based on the ACT/RCPCH categories for use in the weekly multidisciplinary meeting to aid decision making when considering whether children meet the referral criteria for addition to the caseload. The respondent described the efforts to ensure that other professionals (external to the service) have an awareness of which children can access the service as ‘a continuing and sometimes frustrating process’.

Example 2: This service accepts young people less than 19 years of age. Young people referred at 16 years of age and over are considered individually depending on whether they are entering the final phase of their life and when there are no alternative services available to match their choice of place of care. Young people accepted into the service have ‘a condition with no reasonable hope of cure and from which they may/will die in childhood or early adulthood’ or ‘have a condition (or are diagnosed with a condition in the antenatal period) for which curative treatment may be feasible but can fail, such as children and young people with cancer’. Other referrals accepted include: babies born at the margins of viability, where intensive care has been deemed inappropriate and those with postnatal conditions which result in the baby experiencing ‘unbearable suffering’ in the course of their illness or treatment e.g. severe necrotizing enterocolitis where palliative care has been deemed to be in the baby’s best interests.

Example 3: Referrals for this hospice are accepted by post, fax or email and all supporting evidence to confirm the child’s health must be provided. Once a referral is complete it is considered at the weekly multidisciplinary team meeting. Statutory funding must be confirmed as available before a child can be fully accepted onto the service. The thresholds to access the service are children and young people who meet the [ACT/RCPCH] health eligibility criteria, are 0-20 years old and parents must have signed the referral forms (or Local Authority, if the child is under a care order). There is no strict catchment area but for practical reasons the 12 nearest boroughs are served. When a family from further away is referred the hospice will always check that the referrer is aware of more local hospices before processing the referral.

Another respondent referred to their service having specialist pathways of care in place, currently oncology and neonatal end-of-life-care pathways with work being undertaken on a neurological pathway. One service indicated that ‘for counselling for “non-hospice children” death must be traumatic’ with a judgement made on the referral acceptance being made by a panel.

Exclusion criteria

A number of exclusion criteria were mentioned by organisations, including deaths from:

- Sudden accidental death including road traffic accidents;
- Suicide;
- Unlawful killing;
- Stillbirth (>24 weeks). If following a post-mortem it is determined that the baby had a condition that would have met the criteria then a family support referral post-delivery can be accepted;
- Miscarriage;
- A brief sudden onset of illness which resulted in the death of a child.

One service referred to exclusion criteria around pre-existing significant mental health or learning disabilities needs and in those cases, liaison would be supported to other organisations.

Challenges

What are the challenges facing your service and the possible development areas to address them? Consider: capacity; workforce; children, young people and families who are not engaged with hospice services; changing prognosis and expected treatment pathways; transition.
The question around challenges posed to survey respondents offered some suggestions of potential challenges (see above) and a number of respondents simply responded with ‘all of the above’. However, more detail was offered in some responses, which is summarised below.

**Misconceptions around hospice care and services available**

A fear of hospice care on the part of some families was mentioned by a number of respondents. Some indicated that there remains a perception that palliative care is synonymous with end-of-life care ‘rather than being a philosophy of care that is best integrated from diagnosis’. This can result in late referrals and poor patient care. Particular areas of paediatric care were mentioned where this occurs more frequently, namely: neuromuscular, cardiac and renal services.

**Data capture**

The challenge of capturing meaningful data to measure impact was highlighted by a number of respondents. Some respondents also highlighted the need to develop child-specific output and outcome measures, whilst acknowledging the difficulties and sensitivities in measuring these.

**Capacity**

Particular challenges were mentioned around balancing the number of professionals needed to manage a sustainable on-call rota versus a day-time workload. One respondent highlighted the essential need to be able to reliably access out-of-hours support at end of life, particularly for those who will not chose to use the available hospice provision. To support this, improvements need to be made in some regions to children’s community nursing with 24/7 specialist nursing rotation and a fully-funded and sustainable consultant rota. This was reinforced as a gap by other respondents.

Future challenges around capacity were also flagged, particularly considering current and anticipated challenges around workforce recruitment and retention. The pressure placed upon voluntary sector services as a result of funding cuts within the National Health Service (NHS) was also highlighted. Gaps in community care in some areas are also placing local hospice services in greater demand.

**Workforce recruitment**

The recruitment of specialist nurses and other specialist teams (for example psychologists with experience of working with this client group) were highlighted as particular challenges. The challenges of working with more complex caseloads, attributed by respondents to a decreasing capacity across statutory services, were highlighted as a potential reason for increased anxiety amongst the workforce.

Transition to adult services: increased life expectancy amongst children with very complex healthcare needs was emphasised as having an impact upon the demand for skilled nursing care and the transition to adult support services. One respondent stated: ‘The children that are surviving into adulthood are doing so with childhood conditions that adult clinicians are not skilled or experienced to care for. This creates a skills, knowledge and experience gap and negatively impacts on the experience of young adults who need to access adult healthcare.’

**Geography**

Frustrations were mentioned around the lack of cooperation across health board boundaries, for example specialist nurses not being shared across areas. This has meant that a child or young person can have access to a particular team when an in-patient but not when at home after being discharged. Gaps in some services have been identified in particular rural areas, for example neonatal referrals not being available in some local areas, a lack of inpatient hospice care in others and staff being asked to travel increasingly large distances to cover the demand for care. A lack of a consistent approach to care planning across and between regions also featured amongst responses.

**Funding**

One respondent described the understanding amongst health boards of the funding of children’s palliative care services as ‘muddy’ with the specialist palliative care team being spread across six funded local health boards with no single management structure.
A summary of the responses to round one of the survey was sent out to potential respondents of round two. Round two survey questions were structured as follows:

- Respondents were presented with a list of key challenges identified from round one. Respondents were then asked to tick the box of those challenges which applied to their service.
- Respondents were then presented with a list of ‘possible development areas’ to address the identified challenges and asked to tick those which applied to their service.
- A list of different kinds of service identified as part of round was then presented with tick-boxes.
- Finally, a summary of the profile of children and young people using palliative care services based on the responses to round one was included and respondents were asked to offer reflections and comments.

In terms of the different kinds of support offered by each organisation (bullet-point three above), the responses to round two of the survey were broadly reflective of round one responses.

A summary of other responses to round two is provided below. A total of seven complete responses were received to this second round, two of which were from respondents who also completed responses to round one of the survey.

**Workforce challenges**

Responses to the following challenges identified from round one were as follows: 55% identified training and workforce development as a challenge; 45% identified workforce development and 81% workforce recruitment and retention.

Respondents specifically referred to the challenges of matching qualification/training levels and pay-scales within the voluntary sector to those offered within the National Health Service (NHS) (which will likely face its own challenges around a shrinking workforce, especially after Britain leaves the European Union).

**Internal capacity**

Regarding challenges as part of internal capacity, the table below outlines the number of respondents identifying with each challenge.

<table>
<thead>
<tr>
<th>Challenge</th>
<th>Percentage of respondents identifying with this challenge</th>
</tr>
</thead>
<tbody>
<tr>
<td>Funding</td>
<td>1</td>
</tr>
<tr>
<td>Appropriate workforce</td>
<td>6</td>
</tr>
<tr>
<td>Providing 24-hour care</td>
<td>3</td>
</tr>
<tr>
<td>Increasing complexity of conditions and their management</td>
<td>1</td>
</tr>
<tr>
<td>Workforce recruitment and retention</td>
<td>2</td>
</tr>
<tr>
<td>Collecting and analysing data to demonstrate impact</td>
<td>1</td>
</tr>
<tr>
<td>When a child’s condition improves, families can find reduction in support a challenge leading to continued engagement</td>
<td>1</td>
</tr>
<tr>
<td>Collecting and analysing data to support service development</td>
<td>1</td>
</tr>
<tr>
<td>Building/physical capacity of hospice to accommodate families</td>
<td>1</td>
</tr>
</tbody>
</table>
The ability to recruit and retain skilled staff to deal with very complex health conditions was highlighted again as a challenge. The lack of capital grant funding to develop services was also mentioned by a small number of respondents. Other challenges highlighted in this second round (some of which correspond with those identified in round one) were: the challenge of running services in rural areas; availability of specialist nursing staff has been flagged by one organisation as a red clinical risk; different catchments for adult and children’s services which has a resulting impact upon young people who are transitioning to adult services.

**Wider system issues**

Respondents were asked to comment on any ‘wider system issues’ which pose a challenge to their service delivery. The main challenges identified here referred to an identified lack of services available to support children transitioning into adulthood, whilst acknowledging that a ‘lot of work’ has been carried out in recent years around providing guidance on this. Similarly to round one, respondents also referred to the ‘incorrect’ perceptions around palliative care and ‘end-of-life’ care and the lack of understanding of practitioners who are experienced in working with adults but not children. Management of increasingly complex conditions was again reinforced as one of the main challenges to services, both in terms of capacity and ensuring that a full complement of specialist staff is available.

One respondent indicated that their service has seen a ‘sharp rise’ in referrals of children and young people with complex care needs which the respondent attributed to ‘improved levels of understanding and confidence in what children’s hospices can do’. However, another respondent indicated that there are large numbers of potentially eligible children and families who are not accessing hospice care and has suggested that in order to improve access ‘we need better awareness among referrers and particularly parents of the range of services we offer, specifically that it is not just about being nearly at the point of death.’ The same respondent does highlight however that increased referrals will need action to be taken on increasing capacity and addressing shortages in nursing staff. A number of responses highlighted the potential impact of Brexit on nursing and other medical professional staffing levels. The need for further work to evidence the positive impact that holistic hospice care for children can have on unplanned hospital admissions, family mental health interventions and the welfare costs of family breakdown was also highlighted.

One respondent referred to the perception that hospice services are still thought of as a ‘nice to have’ rather than an essential support service to children, young people and their families. Another discussed how models to support service need to be able to adapt to the circumstances of each family: ‘The larger part of living with a life-limiting condition, death, loss and grief takes place away from the children’s hospice. If we want to make the maximum difference to people’s lives the focus must shift towards improving their life experiences for the 94% of the time and for those families that do not access hospice services. The demand for hospice services cannot be met in the future through this traditional model as funding will not keep pace with demand and thus a new approach to the model of care is required.’
The dearth of literature around children’s palliative care in general is widely-acknowledged, with ethical sensitivities of engaging with young people and their families at such a difficult and distressing time being one of the main potential attributions. Much of the literature within this sector therefore (with some exceptions) is concerned with the commissioning and delivery of services and the experiences of staff rather than empirical work with children, young people and their parents/carers. Much of the literature acknowledges this and calls for more intentional participatory work around including the voices of children, young people and their parents/carers. Literature which is concerned with documenting the ‘illness experience’ of children and young people usually focuses on one discrete aspect of that experience, for example, sleep, particular surgical interventions, PTSD, management of pain and management of symptoms. Choices and decision-making processes around place of care is one of the themes of the literature which crosses between the experiences of children, young people and their families on the one hand and staff on the other, focussing as much of the literature around this theme does on staff-patient communication and preconceptions of palliative care.

In relation to service delivery, the literature mainly focusses on divergent themes: staff training, capacity and staff coping mechanisms; the commissioning of services with a particular focus on geography and bordering in the planning of support; funding; and examples of local settings.

There are certain themes within the literature which cross-fertilise with the findings of the two-stage survey carried out, namely: the misconceptions around hospice care, the availability of specialist staff and staff capacity and the challenges of commissioning services across regions.

Hospices and other palliative care service providers were approached for their responses in a two-stage Delphi-style survey which elicited views on: the profile of children and young people using the service; the nature of the service provided; referrals, access routes and any exclusion criteria; and challenges. The findings of the survey were based on 18 responses to stage one and seven responses to stage two from hospices and other palliative care providers between December 2017 and January 2018.

Profile of children and young people accessing hospice and palliative care services

One third of providers who responded to the survey indicated that they support children and young people up to the age of 18. Smaller numbers of responses indicated other age ranges and specifically mentioned providing support during the transition stage from children to adult services. Almost all respondents highlighted the diverse nature of the support provided depending on the needs of the young person, especially emphasising the relationship between the length of support and the diagnostic stage at which the referral is made. Most respondents referred to accepting referrals of children and young people (and their wider family members) who have ‘life-limiting, ‘life-shortening’ or ‘life-threatening’ conditions as defined by the ACT/RCPCH. Some respondents indicated that some of the young people they support may not be referred with a specific clinical diagnostic condition but may present with symptoms indicating that they would meet one of the four categories as outlined by the ACT/RCPCH.

14 Formerly the ACT, now Together for Short Lives
Nature of service provided

Almost all responding services indicated that they provide support to parents/carers, siblings and wider family members. More than half of respondents provide respite care of different lengths of stay (usually between 17-25 days), counselling and specialist play/play therapy. Nearly half of services offer support to bereaved children/young people and music therapy. Approximately a third of services provide symptom management support, art therapy and support provided via outreach or at a place of choice. Smaller numbers of providers report offering more specialist services, such as: chaplaincy/spiritual care; complementary therapies; specialist nursing support; hydrotherapy; physiotherapy; interactive sensory room; crisis care; long-term ventilation support; legal advice; peritoneal dialysis respite; aromatherapy support; dad and male carers support group; parallel planning; anticipatory care planning; support to teachers and other school staff; school projects where children can meet adult patients who are living with a palliative condition. However, as the total number of respondents was only 18, these figures are presented as indicative of the profile of this group of 18 only and should not be interpreted as applying to the provision of hospice services or palliative care more generally.

Referrals, access and exclusion criteria

The majority of responses indicated that referrals can be made by a healthcare professional (HCP) or by a parent/carer. HCPs mentioned as the principal sources of referral included: paediatric wards of acute hospitals; tertiary centres such as Great Ormond Street Hospital; social workers; school nurses; General Practitioners (GPs); children’s community nurses; nursery nurses; clinical nurse specialists; paediatricians; health visitors; foetal medicine; neonatal services and allied health professionals. A number of exclusion criteria were mentioned by organisations, including deaths from: sudden accidental death including road traffic accidents; suicide; unlawful killing; stillbirth; miscarriage; brief sudden onset of illness which resulted in the death of a child. One respondent referred to exclusion criteria around pre-existing significant mental health or learning disabilities needs.

Challenges

The following challenges were identified through the two rounds of the survey.

The need to address possible misconceptions around the nature of hospice services and palliative care in general was highlighted across the breadth of responses and in particular the resulting impact of late referrals and an observation that potentially-eligible children and young people are not accessing services to which they would be entitled. However, whilst recognising that greater numbers of children and young people could potentially be encouraged to access palliative care services, conversely, capacity was also highlighted as an issue by a number of respondents. Particular gaps were emphasised in relation to community care and the challenges of providing round-the-clock support. Capacity was considered by most respondents as an ongoing challenge with the combined potential jeopardies of: the difficulties of recruiting and retaining specialist, qualified and trained staff; the resulting pressures on the voluntary sector of funding cuts within the NHS; and the potential impact of Britain leaving the European Union on staffing levels.

Challenges around capturing meaningful impact data when supporting this particular group of children and young people were highlighted along with the sensitivities of data capture. Transition to adult services was a reported area of concern, particularly the challenges of having experienced staff to work with those who present with complex healthcare conditions, diagnosed in childhood and continuing into adulthood.

In relation to the commissioning of services, the variation in available services across regions was a reported issue, with particular gaps identified in some rural areas, the differences in catchment support areas for children and adults being a concern and the need highlighted for greater cooperation in the planning of services across areas.
References


Please refer to the terminology definitions included as an appendix to this report
Hospice – Hospice UK, in offering the following definition of hospice care, acknowledges the breadth and diversity of services which can be offered under the understanding of hospice service provision:

‘Hospice care aims to affirm life and death. It means working with and within local communities to tailor palliative care around the needs of each adult and child with a terminal or life-shortening condition, whatever that may be, and extends to supporting their carers, friends and family before and after bereavement.

Hospice care is provided by multi-disciplinary teams of staff and volunteers who offer expert support that places equal emphasis on someone’s clinical, physical, emotional, social and spiritual needs with the understanding that everyone will be different.’

This diversity of services is reflected in the responses to the survey detailed in this report.

Palliative Care – The World Health Organisation (WHO) defines palliative care as follows:

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

• provides relief from pain and other distressing symptoms;
• affirms life and regards dying as a normal process;
• intends neither to hasten or postpone death;
• integrates the psychological and spiritual aspects of patient care;
• offers a support system to help patients live as actively as possible until death;
• offers a support system to help the family cope during the patient’s illness and in their own bereavement;
• uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
• will enhance quality of life, and may also positively influence the course of illness;
• is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.  

Children’s Palliative Care – WHO defines palliative care for children and their families as follows:

• Palliative care for children is the active total care of the child’s body, mind and spirit, and also involves giving support to the family.
• It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
• Health providers must evaluate and

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16 WHO Definition of Palliative Care, available at: http://www.who.int/cancer/palliative/definition/en/ Last accessed November 2018
alleviate a child’s physical, psychological, and social distress.

- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.

- It can be provided in tertiary care facilities, in community health centres and even in children’s homes.  

Together for Short Lives also emphasise the diversity and holistic nature of children’s palliative care.  

Children – The United Nations Convention on the Rights of the Child defines a child as everyone under 18 unless, ‘under the law applicable to the child, majority is attained earlier’


Young people – The UK Special Educational Needs and Disability code of practice: 0-25 years defines a ‘young person’ as a person over compulsory school age and under 25. According to the code, compulsory school age ends on the last Friday of June in the academic year in which they become 16 (Department for Education and Department of Health, 2015).

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