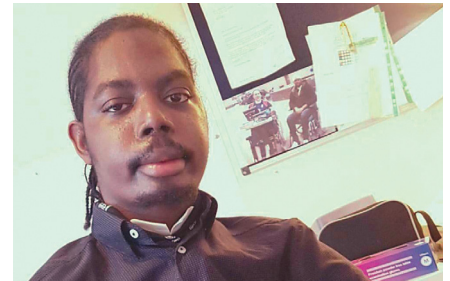


End of life care: strengthening choice

An inquiry report by the All-Party Parliamentary Group
(APPG) for Children Who Need Palliative Care

October 2018





End of life care: strengthening choice is published by The All-Party Parliamentary Group (APPG) for Children Who Need Palliative Care, England.

First published in 2018



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ISBN: 1 898 447 40 3

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This report was researched and written by James Cooper, Public Affairs and Policy Manager, Together for Short Lives. It was funded by Together for Short Lives.

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Design: Qube Design Associates Ltd

Photography: Thank you to all the families who shared their photos as part of the report and to CHAS, Demelza Hospice Care for Children, Julia's House Children's Hospice, Keech Hospice Care, and Martin House Children's Hospice for the photos used in the body of the report. Special thanks to the children and young people featured on the cover: Daisy Nimmo, David Langton-Gilks, Junior Jimoh, Keir Platt, Lennon Ruffles, Lucy Watts, Daniel Strawson, Lexi Kerr, Effie Hadman.

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List of abbreviations

ACP	– Advance Care Plan
ALB	– Arm’s Length Body
APPG	– All-Party Parliamentary Group
CCG	– Clinical Commissioning Group
CCN	– Community Children’s Nursing
CDOP	– Child Death Overview Panel
CHAS	– Children’s Hospices Across Scotland
CPD	– Continuing Professional Development
CQC	– Care Quality Commission
CSDS	– Community Services Dataset
CYPACP	– Child and Young Person’s Advance Care Plan Collaborative
DCP	– Disabled Children’s Partnership
DCN	– Diana Children’s Nurse
EACH	– East Anglia Children’s Hospices
EHC	– Education, Health and Care
FOI	– Freedom of Information
GOSH	– Great Ormond Street Hospital
HEE	– Health Education England
HR	– Human Resources
ICS	– Integrated Care System
IPC	– Integrated Personal Commissioning
LETB	– Local Education and Training Board
MCN	– Managed Clinical Network
NICE	– National Institute for Health and Care Excellence
NMC	– Nursing and Midwifery Council
PHB	– Personal Health Budget
POON	– Paediatric Oncology Outreach Nurse Specialists
PPM	– Paediatric Palliative Medicine
PPM CSAC	– Paediatric Palliative Medicine College Specialist Advisory Committee
RCN	– Royal College of Nursing
RCPCH	– Royal College of Paediatrics and Child Health
SEN	– Special Educational Needs
SEND	– Special Educational Needs and Disability
STP	– Sustainability and Transformation Partnership
VCS	– Voluntary Care Sector
WTE	– Whole Time Equivalent

Foreword

49,000 babies, children and young people are living in the UK with health conditions that are life-limiting or life-threatening and the number is rising: 40,000 live in England alone.

Hearing the news that your child has a life-limiting condition and is likely to die young is devastating. It's an incredibly distressing and confusing time. These children have very complex and unpredictable conditions and often need round the clock care, seven days a week.

Families have to cope with the knowledge that their child will die before them, and daily life for the whole family can become challenging. Although there are many excellent services helping them, many families still have difficulties accessing the care and support they need.

Children with life-limiting conditions need palliative care from the point at which their condition is diagnosed or recognised until the end of their lives. Families also need care and support throughout the trajectory of their child's illness, including bereavement care after they have died. Palliative care for children includes, but is not limited to, end of life care, and the two terms should not be used interchangeably.

These children and their families rely on palliative care provided in hospital, children's hospices and in the community, by the statutory and voluntary sectors. Children's palliative care providers offer a range of services, including supporting families to manage their children's pain and distressing symptoms, providing children and their families with life-line short breaks and offering bereavement support both before and after the child has died.

Families want to be able to choose where they receive the lifeline children's palliative care services that they rely on, when they need and want them. They also want to choose who cares for their child and which treatments they receive. However, the extent to which children and their families can access the palliative care they need – and make meaningful choices about how and where they receive it – varies considerably across England.

As the All-Party Parliamentary Group (APPG) for Children Who Need Palliative Care, we seek to educate, inform and motivate Parliamentarians to take action to help transform the lives of children and young people across the UK with life-limiting and life-threatening conditions. We are supported to do so by our secretariat, Together for Short Lives, the UK's leading charity for the 49,000 children living with life-limiting conditions, and their families.

Through our inquiry, we have been examining the extent to which the government is meeting its end of life care choice commitment for the 40,000 babies, children and young people in England with life-limiting and life-limiting conditions. In doing so, we have examined how children's palliative care is provided in other parts of the UK.

We have identified a number of challenges which, if not quickly met by the government, will threaten ministers' ability to meet their end of life care choice commitment for children by 2020. We urge the government to work with us to implement the recommendations we make.



Catherine McKinnell MP
Newcastle Upon Tyne North
Co-Chair



Dr Caroline Johnson MP
Sleaford and North Hykeham
Co-Chair and Consultant Paediatrician

Executive summary

The government's commitment to the 40,000 babies, children and young people in England with life-limiting and life-threatening conditions is clear and welcome.

While we are concerned that the terms palliative care and end of life care are often (wrongly) used interchangeably, we support the commitment's unambiguous statements which set out both the choice, control and personalised services that children and their families should expect and the extent to which they should be planned and provided by professionals and organisations around them.

Despite the commitment, the reality is that the quality of palliative care that children and families can access is patchy and depends on where in England they live. This is limiting the choices they can make about the palliative care they need. It is also unfair and represents a wholly unjustified health inequality. We have identified five areas of particular concern:

1. Access to children's palliative care out of hours and at weekends: The National Institute for Health and Care Excellence (NICE) states¹ that children with life-limiting conditions who are approaching the end of their lives and are being cared for at home should have access to advice from a children's palliative care consultant (for example by telephone) and children's nurses at any time (day and night). This is critical in making sure that children with life-limiting conditions and their families can choose to receive palliative care at home. However, professionals providing palliative care to children at home only sometimes:

- have 24/7 access to specialist medical advice on managing complex symptoms
- have 24-hour access to advice from a children's palliative care consultant
- are able to provide 24-hour multi-disciplinary children's palliative care at a child's home.

There is a major discrepancy between services planned and funded ('commissioned') between 8am and 6:30pm Monday-Friday and services commissioned to provide care out of hours. 93% of clinical commissioning groups (CCGs)

commission community children's nursing (CCN) teams, but just 67% commission them to provide care out of hours. Although 64% of CCGs commission services to provide community paediatricians, only 29% commission them to provide out of hours care.

2. Access to short breaks (respite): Children with life-limiting conditions and their families rely on frequent short breaks for respite, provided by skilled people who can meet their often complex needs. This may be for only a few hours – or overnight for a few days at a time. The 24/7 pressure on parents of having a child with a life-limiting condition is immense, so social care is vitally important to relieve this stress, catch up on sleep, spend time as a family and do the things that other families do. NICE recognises the need for short breaks in its guidance¹. However, we have heard evidence from parents who have been unable to access short breaks when they needed them most. Too few CCGs and local authorities in England plan and fund short breaks for children who need palliative care and many argue about who is responsible:

- More than one in five (21%) local authorities are failing to meet their legal duty to commission short breaks for disabled children with life-limiting and life-threatening conditions
- Only 68% of CCGs reported that they commission services for children with life-limiting and life-threatening conditions jointly with their local authorities
- Fewer than half (49%) of local authorities reported that they jointly commission these services with CCGs

Where CCGs and local authorities fail to plan and fund short break services for children with life-limiting conditions, families have little alternative other than admitting their children to hospital when they reach breaking point.

3. Access to age-appropriate palliative care and smooth transitions to adult services: For young people with life-limiting conditions, making the transition from children's to adult services can feel like falling off a cliff edge. Medical advances mean there are now 55,000 young adults aged between 18 and

40 with life-limiting conditions and this figure continues to grow. However, the transition these young people have to undergo from the comprehensive care offered by children's palliative care to unfamiliar adult services can be daunting and is often not joined up. There are also too few palliative care services which meet the needs and wishes of young people in ways which are appropriate to their age and developmental stage. Only 50% of young people and their parents say that they had received support from a lead professional during the process leading up to transition to adult services. One in six (16%) CCGs are not commissioning age and developmentally appropriate services. Furthermore, a similar proportion (15%) of CCGs do not take steps to ensure that these young people experience smooth transitions from children's to adult palliative care services.

- 4. Access to specialist children's palliative care teams led by Level 4 consultants:** NICE states that children with life-limiting conditions should be cared for by defined multidisciplinary teams (MDT)¹ which include members of specialist children's palliative care teams. Children with life-limiting conditions usually receive coordinated care, provided by a MDT, which have access to medical advice provided by Level 3 children's palliative care consultants. These consultants are able to provide elements of specialised children's palliative care, including prescribing alternative opioids and managing complex symptoms². However, NHS England states³ that specialist children's palliative care teams should be led by medical consultants working at Paediatric Palliative Care Competency Level 4². These consultants are vital because they:

- can manage uncommon symptoms
- are able to advise on medical support for which there is no evidence base
- lead and develop services within and beyond a local children's hospice
- support and teach other professionals who are not trained in palliative medicine.

We have found that, across England, specialist children's palliative care teams are only sometimes led by Level 4 consultants.

- 5. Access to advance care planning:** NICE states¹ that professionals should develop and record an advance care plan (ACP) at an appropriate time for the current and future care of each child or young person with a

life-limiting condition. ACPs help to set out the needs and wishes of children and their families and can help to make sure that their choices are realised. Despite this, only some areas are undertaking advance care planning.

The barriers to choice and what we recommend to overcome them

We have identified five barriers which explain why the government's choice commitment is at serious risk of not being met and where there are opportunities for government ministers and officials, working with partners including NHS England and Health Education England, to work to overcome:

- 1. Leadership and accountability:** the way in which NHS CCGs and local authorities plan, fund and monitor (a process known as 'commissioning') children's palliative care in hospitals, children's hospices and the community represents a postcode lottery. Almost half (46%) of CCGs are failing to implement the government's end of life care choice commitment and have no plans to do so. Only a third (35%) of CCGs responded that they are implementing this guidance, while a further 19% stated that their plans to do so are in development.
 - We call for the government's mandate to NHS England – and the forthcoming NHS 10-year plan – to specify that the end of life care choice commitment be implemented in full for babies, children and young people.
 - The government and NHS England should consider appropriate mechanisms to bridge the children's palliative care accountability gap. They should develop a system to monitor how sustainability and transformation partnerships (STPs), integrated care systems (ICSs), CCGs and local authorities are supporting children's palliative care in accordance with their legal duties.
 - We call on the government to develop outcome indicators which measure the extent to which children with life-limiting conditions and their families can make choices about the palliative care they receive. They should reflect the outcomes set out in the NICE quality standard for end of life care for infants, children and young people⁴.

- More widely, the government should specify in the mandate to NHS England – and the forthcoming NHS 10-year plan – that physical and mental health services for babies, children and young people with long-term disabilities should be commissioned, resourced and provided.
- 2. Clarity:** Poor commissioning is often caused by CCGs and local authorities being confused about the elements of children’s palliative care they are responsible for commissioning. Most typically, CCGs and local authorities are confused about who commissions short breaks (respite) for children with life-limiting conditions and specialised children’s palliative care.
- We call on the Secretaries of State for Health and Social Care and for Education and the chief executive of NHS England to write to STPs, ICSs, CCGs and local authorities to clarify which parts of the health and care system in England are responsible for commissioning palliative care for children and young people aged 0-25. This should make clear who is responsible for commissioning short breaks and specialised children’s palliative care, as described by NHS England³.
 - NHS England should develop service specifications for children’s palliative care, which span generalist to specialised care provided in a range of settings.
- 3. Funding:** the children’s palliative care provided by voluntary sector organisations, including children’s hospices, helps ease pressure on the NHS. Children’s hospices, for example, make a crucial contribution to local health economies. Without them, this clinical care would otherwise have to be provided and paid for in its entirety by the NHS. However, the statutory funding they receive from NHS England, CCGs and local authorities is patchy and unsustainable. These challenges are being exacerbated by the government’s decision not to provide financial support to help voluntary sector providers who do not apply Agenda for Change pay and conditions to mitigate the recent pay rise for non-clinical NHS staff. More personalised approaches to assessing children’s needs and desired outcomes, as well as to planning and funding the care they need (including through more children having access to a personal budget) has potential to increase choice and control for families. However, we caution that personal budgets are not appropriate for all families. The government and NHS England should go further to make sure that children’s palliative care is funded equitably and sustainably in England. NICE calculate that by investing £12.7million in implementing its guideline on children’s palliative care¹, non-cash savings worth £34.7million would be released back into the NHS in England⁵.
- We call for the overall amount of funding available through the NHS England Children’s Hospice Grant to be increased to £25million to reflect the growth in demand, costs and complexity of care needed by children and young people with life-limiting or life-threatening conditions.
 - We call on the government to bring about parity in the state’s percentage contribution to the charitable costs incurred by children’s and adult hospice and palliative care charities. This would mean that children’s organisations would receive at least 33% of their charitable costs, comprising contributions from NHS England, CCGs and local authorities. We note that the Scottish Government has committed to bring about parity and fund 50% of the agreed charitable costs of Children’s Hospices Across Scotland.
 - The government should undertake a review of the children’s palliative care currently available to children with life-limiting conditions in England as a matter of urgency. This should lead to a funded, cross-departmental children’s palliative care strategy for achieving better outcomes for children and families across the statutory and voluntary sectors. It should bring about greater access to funding for services providing emotional and practical support for families in the community. It should also include a review of the way in which short breaks for disabled children, including those with life-limiting conditions, and families are funded.
- 4. Workforce:** There are too few professionals with the skills, knowledge and experience needed to provide children’s palliative care in hospitals, children’s hospices and in the community. Specific skills are needed when speaking to children and families about the choices available to them and developing advance care plans with them; shortages in children’s nurses and children’s palliative care consultants are particularly acute.
- We call on the government’s mandate to Health Education England to specify the need for a health and care workforce in England which can meet the end of life care choice commitment for babies, children and young people.

- We call on Health Education England to assess the demand for nurses from voluntary sector children's palliative care organisations and include it in their planning models – and develop a competency framework for providing children's palliative care.
 - We call on Health Education England and the Council of Deans of Health to work with the Royal College of Paediatrics and Child Health, the Royal College of General Practitioners, the Royal College of Nursing and Together for Short Lives to develop a children's palliative care training and education model. This should help make sure that all professionals – both specialist and general – who provide care for children with life-limiting conditions have the necessary skills and knowledge.
 - We call on the Council of Deans of Health to encourage university undergraduate nurse programmes to adopt the new Nursing and Midwifery Council (NMC) standards for nurses⁶, including those elements which relate to providing children's palliative care.
- 5. Integration:** single, joined-up education, health and care (EHC) assessments, plans and personal budgets for children and young people up to the age of 25 are only available to children and young people who have a special educational need. We are also unclear as to how the government's approach to
- personalising palliative care for children and young people, which is also underpinned by joint plans and budgets, correlates with the SEND system. NICE recommends that children's palliative care services should be based on managed clinical networks (MCNs) and should collaborate on planning and providing care. However, East of England is the only region in England which has a children's palliative care MCN.
- We believe that the government should make sure that all 40,000 babies, children and young people in England with life-limiting or life-threatening conditions should have the right to an integrated assessment, plan and personal budget.
 - We call on the government to commission a review of health and social care law, to strengthen and clarify rights and entitlements for disabled children and their families, including children with life-limiting conditions. This would help to bring about more integrated assessments and plans.
 - We urge the government and NHS England to invest in supporting work to develop children's palliative care MCNs across the country.



How we have conducted our inquiry

“It’s about living...paediatric palliative care is about making the most of what you’ve got.”

Dr Simon Clark, oral evidence session three



1. In November 2017, we began a select committee-style inquiry into the extent to which the government is meeting its end of life care choice commitment for babies, children and young people. The commitment, entitled ‘Our Commitment to You for End of Life Care: The Government Response to the Review of Choice in End of Life Care’⁷, states the following:

Our commitment to you is that, as you approach the end of life, you should be given the opportunity and support to:

- have honest discussions about your needs and preferences for your physical, mental and spiritual wellbeing, so that you can live well until you die
- make informed choices about your care, supported by clear and accessible published information on quality and choice in end of life care; this includes listening to the voices of children and young people about their own needs in end of life care, and not just the voices of their carers, parents and families
- develop and document a personalised care plan, based on what matters to you and your needs and preferences, including any advance decisions and your views about where you want to be cared for and where you want to die, and to review and revise this plan throughout the duration of your illness
- share your personalised care plan with your care professionals, enabling them to take account of your wishes and choices in the care and support they provide, and be able to provide feedback to improve care
- involve, to the extent that you wish, your family, carers and those important to you in discussions about, and the delivery of, your care, and to give them the opportunity to provide feedback about your care
- know who to contact if you need help and advice at any time, helping to ensure that your personalised care is delivered in a seamless way.

‘Our Commitment to You for End of Life Care’: page 10

2. The government has stated that it believes there is scope for the commitment to be included as a pledge in the NHS Constitution by 2020. It has also said it is considering reflecting the commitment as a section in the NHS Choice Framework. The government is clear that the commitment applies to people of all ages who need palliative care:

“Our Commitment to end of life care is for people of all ages: children, young people and adults. Similarly, most of the measures we have set out to deliver the commitment apply equally to people of all ages needing end of life care. Children and young people with the most complex needs should be able to live their lives as they and their parents wish, and enjoy the same independence and choice which we all expect. As we have reflected in our Commitment, it is essential that the voices of children and young people are heard so that they are involved in their care, able to express their needs and preferences and make informed choices about their care.”

‘Our Commitment to You for End of Life Care’: page 36

3. The government is also clear that commissioners must actively plan and fund palliative care:

“To support high quality personalised care for children and young people, commissioners and providers of services must prioritise children’s palliative care in their strategic planning so that services can work together seamlessly and advance care planning can be shared and acted upon. Commissioners should also consider how they can structure services that offer accessible, high quality respite and bereavement support for children and their families.”

‘Our Commitment to You for End of Life Care’: page 36

4. To realise this commitment, on page 37 the government states:

- “We will explore with commissioners, NHS providers and the hospice sector how best to encourage a dialogue on commissioning well-coordinated palliative and respite care, and different approaches to funding locally commissioned services, using the palliative care currencies as ‘building blocks’.”
- “NHS England will explore the scope for Integrated Personal Commissioning (IPC) to include end of life care services. IPC is a new way to support both adults and children with complex needs by joining up health, social care and other services at the level of each individual. The approach focuses on person-centred care and support planning, facilitating an earlier, more personalised discussion of end of care for those with the most complex needs.”
- “NHS England will work with a small number of interested areas to assess rapidly the options for personalising services and improving choice and control for individuals at end of life, using the learning from the delivery of personal health budgets and integrated personal commissioning in end of life care, including for children.”

5. In September 2017, [the government’s ‘One Year On’ report](#)⁸ gave an update on the progress achieved in meeting the end of life care choice commitment. It cites the National Institute for Health and Care Excellence’s (NICE) guideline ‘End of Life Care for Infants, Children and Young People: Planning and Management’¹, published in December 2016, as an important step forward. NICE has also recently published a quality standard on the same topic⁴, another important guide to help the NHS, voluntary and private sectors better plan, fund and provide children’s palliative care.



6. Through the inquiry, we have been seeking views on the following questions:

1. What choices can children and young people in England with life-limiting and life-threatening conditions – and their families – reasonably expect to make about the care and support they receive? Do these vary in relation to different conditions?
2. Can children and young people in England with life-limiting and life-threatening conditions make these choices? To what extent is this the case? Is this being measured – and, if not, can it be? Do these vary in relation to different conditions?
3. What are the barriers preventing children and young people from making these choices? Do these vary in relation to different conditions? Are there barriers which are preventing services from offering choices?
4. What are the opportunities for improving the extent to which children and families can make these choices? What policies do the government, NHS England and others have in place to improve choice for children? Are there examples of where children and families have been offered choices that others can learn from, including from Northern Ireland, Scotland and Wales?
5. What actions can the following individuals and organisations take to improve the extent to which children and families can make these choices?
 - Children and young people with life-limiting or life-threatening conditions
 - Families
 - Providers of children’s palliative care in the statutory, private and voluntary sectors
 - Government
 - NHS England
 - NHS commissioners
 - Local authorities
 - Workforce planners
 - Educators
 - Charities, including Together for Short Lives.

7. This report seeks to answer these questions, informed by the written and oral evidence we have received. As a result of our call for written evidence, which began on 24 November 2017 and ended on 15 January 2018, we received 28 submissions. We have published these separately as an annex to this report. Those who submitted written evidence are listed in Appendix Three.

8. Additionally, we received 25 responses to a survey of families caring for children with life-limiting conditions.

9. Following the end of the call for written evidence, we held four oral evidence sessions on the Parliamentary estate. We recorded each one and all are available to download and listen to as podcasts from <https://togetherforshortlives.podbean.com>. Our witnesses are listed in Appendix Three.

Transcriptions of all of the oral evidence sessions are available to download from www.togetherforshortlives.org.uk/appg.

In detail: what we have found and what we recommend

1 The choices that children and young people in England with life-limiting and life-threatening conditions, and their families, wish to make

1. Families who responded to our survey stated that they would like to have (or have had) the ability to choose:
 - to receive short breaks (respite), nursing support or end of life care in a children's hospice or at home
 - to be able to access services which are closer to where they live
 - when they could receive care – for example, overnight care during the week
 - who cares for their child; one parent stated “I would like familiar people around to support me. Not agency staff that I've never met.”
 - the location in which they could access nursing support
 - to access certain treatments that are not available to them
 - more information to help them better understand choices and guidance.

“At present we only get respite care when we are told we can have it. It's often cancelled at last minute due to others requiring end of life care, which is totally understandable, but no consideration is then given to how many cancellations have been made in order to perhaps bring forward or increase future offers of care to catch up on the shortfall.”

[A family respondent to our survey](#)

“Nine to five, my community nurses were amazing, but come five o'clock in the evening, you're very alone. It's a massively overwhelming responsibility keeping a child alive. When you're out there on your own and you've got no support it's hard – emotionally hard. If you were in hospital, it would be a consultant making those decisions. When you are at home, it's you.”

[Nikki Lancaster, oral evidence session four](#)

2. Families said that the following actions could help to improve the choices on offer to them:
 - A greater number of short breaks
 - Access to community nurses at home to provide care such as administering antibiotics and advising about medication and equipment
 - Social care and housing services arranging support more quickly to help make sure that children can leave hospital sooner

3. NICE states¹ that professionals should develop and record an advance care plan (ACP) at an appropriate time for the current and future care of each child or young person with a life-limiting condition. ACPs help to set out the needs and wishes of children and their families, and can help to make sure that their choices are realised.
4. The extent to which children and their families can make meaningful choices about how and where they receive palliative care – and record them on an advance care plan that all professionals who provide them with care and support plan can access – varies considerably across England. It depends on whether or not:
 - the complexity of the child’s condition enables different options for how and where palliative care is provided to be offered
 - there is more than one way of meeting the child’s best interests
 - a range of children’s palliative care services provided in hospital, children’s hospices and the community is planned, funded and delivered within a local area
 - there are enough professionals with the skills, knowledge and experience needed to provide these services in different settings and to speak to children and families about the choices available to them and develop an advance care plan with them
 - transport is available to take children from one setting to another at short notice and whether rapid discharge protocols are in place
5. There is little that can be done to offer choices to families if their child’s condition is too complex – or if their best interests can only be met in one location, for example. However, we strongly believe that ministers, officials, commissioners, services, professionals and educators all have a role to play in making sure that a range of children’s palliative care services are available in every area of England. They should also work to make sure that sufficient numbers of professionals are available to provide this range of services and help families to make advance care plans – if this is what families want.
6. Data that conclusively determines where families’ preferred place of death is for children with life-limiting or life-threatening conditions is scant. A study conducted by Professor Myra Bluebond-Langner et al⁹ reviewed nine studies from five countries. Six reported a majority of parents (only one study interviewed adolescents) expressing preference for death at home. Other studies differed significantly in their findings; one reporting 35% and none preferring death at home. Some parents did not express a preference. Six of the studies included only parents of children who died from cancer while being treated at tertiary centres that offered palliative care services. The study concluded that the evidence base for needing to increase home death rates for children and young people with life-limiting and life-threatening conditions is inadequate. It recommended further rigorous research to collect data from parents, children and siblings.
7. Based on the experience of Children’s Hospices Across Scotland (CHAS), children and young people in need of palliative care and their families can make the choice of how they would like their life to be and where they would like to die, providing that they get the right information and support. A vital part of CHAS’ services is the Diana Children’s Nurses (DCNs). The DCNs are three nurses who specialise in different areas of children’s palliative care, and they are based in the West, East and North of Scotland and predominantly work within the NHS but are employed and supported by CHAS. They work directly with families and alongside health and care colleagues on matters concerning children’s palliative care as well as providing training and developing local and national guidance and policy¹⁰.



“We’ve got the generalised care plan that changes over time then we’ve got this end of life plan that, I think it’s been changed a couple of times, but actually although I haven’t made an advance directive and decided that actually I don’t want this or I don’t want that, actually my wishes and where I want to be and who I want to be cared for are written down...actually that’s really important and I think it comes back to peace of mind. I know that whatever happens that care plan is there so everyone all know my wishes.”

Lucy Watts, oral evidence session one

8. We have found that the extent to which children and their families can access the palliative care they need, make meaningful choices about how and where they receive palliative care – and have an opportunity to record them on an advance care plan that all professionals who provide them with care and support plan can access – varies considerably across England.
9. A majority of families of children with life-limiting conditions who responded to our survey felt that they had too little choice about how and where their child received palliative care. Others felt that the choices they were offered were about right. No families felt that they had too much choice.
10. Families who stated that they did have choices cited the ability to decide between receiving care in their local children’s hospice or at home, although some stated that this was restricted by whether beds were available. One family cited the positive experience of having an option of their child receiving end of life care at home, in hospital or in a children’s hospice. They stated that they were able to change their minds, right up until the end.
11. Families who said that they were unable to choose cited the fact that only one local children’s palliative care provider could meet their needs. Some mentioned that they had been unaware of services provided in their local area. Others explained that their choice was now very limited because the number of hours of support they were offered at home had been “slashed in recent months”. One family cited the distance they had to drive to access their local children’s hospital as a barrier to their choice.

“I’ve got the generalised care plan and that’s got a statement of my life as it is now but the end-of-life planning I’ve got my preferred priorities of care – so where I want to be cared for and who by – and then I’ve got preferred place of death, so if I do come to the end my life, where I want to be. I’m on the local end-of-life register so that if anything does suddenly deteriorate it’s flagged up.”

Lucy Watts, oral evidence session one

12. In 2017, Together for Short Lives surveyed children’s palliative care networks to determine the extent to which the NICE guideline on ‘End of life care for infants, children and young people with life-limiting conditions: planning and management’¹ is being implemented by providers across England. This work was commissioned by NHS England and is helpful in determining the extent to which children and families can make choices about the care they receive. It found that:
 - NHS trusts mostly or usually make sure that every child approaching end of life has 24-hour access to paediatric nursing care, at least sometimes or usually¹¹
 - NHS trusts mostly or usually make sure there is a rapid transfer process for children and young people with life-limiting conditions to allow urgent transfer to the preferred place of care¹⁴
 - professionals always or usually say that they consider how best to communicate with parents, including care after death and have processes in place if the family wish to have a rapid transfer to their preferred place of death at end of life

- most parents or carers of babies, children and young people are offered support for their grief and loss both before and after their child has died. However, many experience long waiting times and a variable availability of services.

13. Across England, children, young people and their families sometimes¹⁴:

- had access to an ACP
- have access to emotional, psychological, religious and/or spiritual support
- offered bereavement support when their child is nearing the end of their life and after their death; they have found there are some gaps and identified long waiting lists in some areas for bereavement support.

14. Children's palliative care providers have also given us a range of views on this question. In Coventry and Warwickshire, children's palliative care services are integrated into the local community children's nursing (CCN) teams and are able to offer sustainable 24/7 services with medical cover at end of life. This enables families to choose care at home if they prefer. The CCN team states that it works closely with its local hospices to support care there if necessary¹².

"We are finding that more and more children are spending longer and longer in hospital when they could be in another location."

Francis Edwards, oral evidence session two

15. Acorns Children's Hospice Trust feel that, while there are good variety of choices on offer, at the point of diagnosis children, young people and their families should be signposted to all organisations, support groups and palliative care choices who are able to help them at some point on their journey. They also see early referral as being crucial in ensuring families access the best support¹³.

16. Dr Fauzia Paize, a consultant neonatologist based at Liverpool Women's Hospital NHS Foundation Trust, identifies a number of areas that provide an opportunity for autonomy and self-definition for the care that families have access to, though recognises that these are not available around the clock. She also identified the variation of these, depending on the specific condition and the age of the child. Early intervention is crucial to ensure that families benefit from the best possible care¹⁴.

17. In its written evidence, RCPCH state their concern about the extent to which families can make choices. It states that over recent years poor community resource has been highlighted as a growing concern, particularly the lack of community children's nurses able to support complex end of life care. Additionally, it states that many children's hospices are unable to support medically complex care. RCPCH states that this significantly affects the extent to which highly complex care can be provided in the community. This is leading to increased access to unplanned care, increased admissions and delayed discharges.

18. The RCN has told us that its members believe that community children's nursing have reduced services; which is limiting the end of life care which can be provided in the child's home.

19. Steph Nimmo cared for her daughter Daisy who was born with a rare, life-limiting, genetic disease called Costello Syndrome. Steph credits early referral to a hospice as being crucial in the care of her daughter and the ability of the family to support her complex needs. It meant she and her husband were able to care for their other children and minimise the risks to Daisy's safety. It was also essential for planning and provided the support needed to create an end of life plan which reflected Daisy's needs and wishes¹⁵.

20. The Rainbow Trust Children's Charity has recognised a number of areas in which families can make choices about the care they receive, although this varies from area to area¹⁶. It states that choices are inconsistent, often late and not always adequately communicated to families. They acknowledge two situations in which these choices are limited:

- Inequality in support available for cancer and non-cancer diagnoses: Rainbow Trust Family Support Workers are acutely aware of the differing levels of support available to families where a child has a cancer diagnosis. For instance, children with cancer receive extra support from Paediatric Oncology Outreach Nurse Specialists (POON nurses). However, the degree of support is still dependent on where they live, with POON nurses in Bristol currently unable to provide end of life support at home owing to staffing constraints, meaning that parental choice may be compromised.
 - Inequality in support for children with undiagnosed or extremely rare conditions: seriously ill children with undiagnosed genetic conditions will often experience less choice in their care and treatment. Without a diagnosis it can be difficult to access information and support. A child may not have a standard treatment plan, and nursing care at home can be harder to access.
21. The West of England Child Death Overview Panel (CDOP)¹⁷ routinely reviews whether children who die as a result of a life-limiting condition have done so in the place they have chosen. In 54 of the 77 (70%) cases which the CDOP has reviewed, the child did die in the family's location of choice. Of this group, 24 families chose for their child to die at a hospice, 14 at home, 12 in hospital and 4 in another place of their choosing.
22. The CDOP found that in 12 of the 77 (16%) cases, the child did not die in the family's location of choice. Of this group, seven families wanted their child to die at home, four at a hospice and one in hospital. In 11 of 77 (14%) of cases the location of choice for the family was not known and therefore it was not known if the child died where the family wished.
23. We note that CDOPs across England are not obliged to collect this information; we have found little evidence of others doing so.
24. In its annual report for the period April 2016 - March 2017, the West of England Child Death Overview Panel stated that it had found that over the five-year period:
- (185/557) 33% of all child deaths occurred at the Bristol Children's Hospital
 - (160/557) 29% at St. Michael's Hospital
 - (67/557) 12% at hospitals within North Bristol NHS Trust (Southmead and formerly Frenchay Hospitals)
 - (32/557) 6% died in a hospice
 - (55/557) 10% died at home or at a relative's residence
 - (46/557) 8% died in other hospitals
 - (12/557) 2% died in other locations. This included deaths abroad and deaths in public places, for example road traffic collisions.
25. A study by Gao et al¹⁸ published in 2016 on the place of death in children with cancer in England between 1993 and 2014 stated that:
- hospice deaths were rare but more than doubled from 6% in 1993-2000 to 13% in 2005-2014
 - home deaths fluctuated at around 40%
 - those aged 0-19 years were more likely to die at home than young adults
 - haematological cancer patients or those with two or more comorbid conditions had higher chances of hospital death
 - deprivation was associated with a reduced chance of home death
 - the region in which the child lived affected hospice but not home deaths
 - the variations in place of death by cause of death, comorbid conditions and deprivation slightly decreased with time.

26. Overall, the study concluded that hospitals and home were the main end of life care settings for children and young people with cancer. Home death rates had barely changed in the past two decades; deaths in hospitals remained the most common but slightly shifted towards hospices. Children and young people with haematological malignancy or with comorbid conditions had persistently high hospital deaths; these cases had an even lower chance of deaths in hospices (50%) than at home.
27. We call on the government to mandate CDOPs to collect data about where children die, and whether children who die as a result of a life-limiting condition have done so in the place they have chosen. This would help commissioners and providers to better understand where end of life care is being provided, and make sure that resources are allocated to children's palliative care services accordingly.
28. Acorns Children's Hospice Trust do not believe the extent to which choice is being offered is being effectively measured but, anecdotally, they see families being referred inappropriately or much too late, meaning intervention and signposting is not effective¹³.
29. A number of those contributing to our inquiry stated that young people and their families experience fewer choices and less control as they transition to adult palliative care services. In CQC's report of its thematic review of children's transition to adult services¹⁹, it concluded that:
- the transition process is variable
 - previous good practice guidance had not always been implemented
 - young people and families are often confused and at times distressed by the lack of information, support, and services available to meet their complex health needs
 - parents and young people are caught up in arguments between children's and adult health services as to where care should be provided
 - in too many instances, care services just stop when children's services end but before adult services begin
 - too often, well-coordinated transitions happen because parents are proactive in coordinating professionals and actively seek help if they need it
 - only 50% of young people and their parents said they had received support from a lead professional during the process leading up to transition to adult services.



“My biggest fear was that Daisy would reach 18.”

Stephanie Nimmo, oral evidence session one

“If I were to be hit by a bus today, then I wouldn’t be worried looking down thinking, well, I’ve got children’s services to pull together to fill some of the gap. In 10 months’ time (when Ben will reach 16 years of age), I’m not sure that services would come together to work to deliver a package to support Ben, because they don’t communicate.”

Doug Morris, oral evidence session one

30. Despite experiencing challenges, Lucy Watts MBE told us that her transition has helped to give her more autonomy over her care:

“As a child my mum was making my decisions and, actually, transition to adulthood was a horrendous time for me. It was it was horrible, but actually it’s given me a lot and it’s giving me that autonomy. I always say I want my mum there. My mum is still a part of all my appointments, all my meetings, everything. But it’s me that makes the decisions and I value that autonomy and the fact that I’m respected for what I say. I think in paediatrics they don’t always take the young person seriously, because they think all the parents have got the overriding decision. But actually, I’m a big believer that you should involve children from as early as possible in their care and in their decisions. For me, I didn’t get involved in my decisions and I got to transition to adulthood and it was a sudden leap into the unknown for me.”

Lucy Watts, oral evidence session one

31. Dr Fauzia Paize suggests that recording the location of end of life care could be an indicator of choice. The number of days that a child stays in hospital instead of at a hospice or at home could give a guide to distribution¹⁴.
32. However, we have learnt that it is challenging to objectively measure the extent to which children and young people with life-limiting conditions are able to make choices about the palliative care they receive, for several reasons. Firstly, not all children and families wish to decide how and where they receive palliative care, nor wish to record them in an advance care plan. Secondly, some families change their mind and decide that they would prefer their child to die in another location to the one which they have specified in an advance care plan.
33. These changes of preference can be for a variety of reasons:
- families are not able to cope with the demands of providing end of life care to their child at home
 - it becomes clear that the child’s needs – and/or their best interests – cannot be met in the previously preferred location of care
 - it may not be possible to locate medicines or equipment needed by the child in their home environment – or there may not be adequate storage space
 - the impact on the child’s siblings or other family members may not become apparent until the end of the child’s life becomes closer.
34. These changes of preference can happen at short notice and at a time close to the child’s death. In these circumstances, it may not be possible for professionals or families to update the child’s advance care plan accordingly. We therefore feel that it would be unfair to measure and hold commissioners, services and professionals to account over the extent to which they realise the choices specified in a children’s advance care plans.
35. We note that NICE has chosen not to include the proportion of children who die in the place they have chosen as quality measure⁴.

3

The barriers preventing children and young people from making choices



The views of families

36. Families who responded to our survey who did not feel that they were able to exercise enough choice over the palliative care their children received cited the following factors:

- They felt that authorities made decisions for them
- They lived too far away from children's hospices that could have provided them with care and support
- There is little to no information on short breaks services in their area
- Too little funding and/or services being cut by local CCGs
- Community professionals without the skills needed to provide end of life care to their child at home. One family said that if they had better understood their child's needs, they may have been able to receive end of life care at home. While they recognised that hospital was a safer clinical setting, they regretted that all of their other children could not be there and that it would have been easier for them to manage the situation at home.

37. Steph Nimmo, the mother of Daisy who was diagnosed with Costello Syndrome, says that she felt that her continuing care support was constantly under threat: "Despite Daisy's worsening health and our complex family circumstances I lived in fear that our care package would be reduced. I worried about the risks of reduced support in the home in terms of my ability to safely care for my daughter. I was administering very complex drug regimens that had the potential to kill Daisy if I made a mistake. During the last year of Daisy's life I had to attend countless meetings and assessments to justify why I needed the level of support I was receiving, time that I should have been spending enjoying precious time with my daughter."

38. Steph also acknowledges the challenges that the complexity of Daisy's condition created. It meant that, with little specialist care available outside of the training received by Daisy's family, the family were very isolated. Her community nursing team were severely understaffed and only worked 9-6, Monday to Friday managing a huge caseload, meaning they were not fully up to speed with Daisy's day to day care. The lack of short breaks and support meant that Steph often felt she could just be a carer and nurse, rather than a parent.

"What I've found, is that I could get respite care during the week and during school term time, but if I needed something during the children's school holidays, it was so hard. When you've got other children in school. Or weekends. Weekends are so hard. I used to look forward to Monday. I would have, in the end, in the last two years of Daisy's life, I had guaranteed two nights a week at the Children's Trust in Tadworth. That was funded by the CCG. That was because my husband was ill. That was a Monday and Tuesday. My other kids were in school. I had to take Daisy to one of my husband's oncology appointments, because I had no one to care for her. It was a really important appointment and I needed to be there because he needed me there as well taking notes. That's where it becomes really, really serious."

Stephanie Nimmo, oral evidence session one

The way in which children's palliative care is provided

39. NICE states that children with life-limiting conditions should be cared for by defined multidisciplinary teams (MDT)¹ which include members of specialist children's palliative care teams. Children with life-limiting conditions usually receive coordinated care, provided by a MDT, which have access to medical advice provided by Level 3 children's palliative care consultants²⁰. These consultants are able to provide elements of specialised children's palliative care, including prescribing alternative opioids and managing complex symptoms. However, NHS England states³ that specialist children's palliative care teams should be led by medical consultants working at Paediatric Palliative Care Competency Level 4²¹. We have found that, across England, this is sometimes, rarely or never the case.
40. Together for Short Lives has found that, sometimes, rarely or never¹¹:
- staff have 24/7 access to specialist advice on managing complex symptoms in children and young people
 - carers of children approaching the end of life have 24-hour access to advice from a consultant in paediatric palliative care
 - every child has access to a 24-hour multi-disciplinary children's palliative care team for care within the home
 - services are delivered by a consultant-led, multi-professional specialist palliative care team across a children's palliative network or managed clinical network (MCN)
 - specialist children's palliative care teams provide clinical leadership in planning, delivering and evaluating children's palliative care services across a children's palliative network or MCN
 - care is led by a medical consultant working at Paediatric Palliative Care Competency Level 4.
41. An additional barrier which was highlighted during our fourth oral evidence session was that some professionals are concerned about discussing advance care plans because they are worried that they could be liable if the child or family's preferences are not met.
42. Acorns Children's Hospice Trust have reported significant variation in how soon statutory professionals refer children and families onto children's hospices. Other barriers acknowledged by Acorns are the misconceptions around hospice care and the difficulties experienced in accessing palliative care when conditions are particularly severe and time consuming for families¹³.
43. Dr Fauzia Paize, a consultant neonatologist based in Liverpool, identified what she believed to be a number of obstructions to children and families making these choices. These included¹⁴:
- The negative perception that palliative care is 'giving up'
 - The lack of effective, age-appropriate communication means children aren't accessing the right support
 - Lack of integration – not all children's hospices are integrated into their local paediatric units or neonatal units
 - Care plans must reflect the specific needs and desires of the patient and be personalised, rather than adopting a 'one-size-fits-all' approach
 - Patchy service provision geographically, leading to a 'postcode lottery'.
44. In its written evidence, Coventry and Warwickshire Children and Young People's Palliative Care Services note that professionals providing active treatment with the aim of curing a life-threatening condition in a child (such as cancer) do not always parallel plan in a timely manner. As a result, palliative care choices are not offered until right at end of life, at which point it may be difficult to rapidly discharge home for end of life care for these children. Likewise, they state that neonates with life-limiting conditions may only be referred for palliative care after they are born, which may cause difficulties in offering preferred place of care at end of life¹².

45. Some of the barriers to doing direct work with families (i.e. holistic support, parental support and support with decision making and planning) were identified by Children’s Hospices Across Scotland (CHAS) as¹⁰:
- a lack of understanding among NHS staff of what palliative care is, which sometimes had a negative impact on the number and timing of referrals made by NHS staff and how well equipped they felt they were to provide palliative care. Additionally, it was found that some NHS staff did not have the confidence or knowledge to support families’ decision-making process on children’s palliative care
 - nervousness among some staff to raise the suggestion of palliative care with families for fear of distressing them, and reluctance on the part of some families to accept that they were at a point where palliative care would be beneficial
 - the limited capacity to respond to palliative care needs from DCNs and NHS staff alike, especially as the need for services increases, but funding does not.
46. Rainbow Trust also emphasised that many children with complex conditions may vary between stable and less stable episodes, and experience repeated relapses and recovery. This can itself be a barrier to exercising choice as to treatment and care¹⁶. Because of these fluctuations, Rainbow Trust state that some families may not identify their child as being in need of palliative care and potentially requiring plans for end of life.

Commissioning

“When it comes to us as commissioners...we have to protect the limited resources we have and focus on our priorities. So for example, social services, their priority is child protection, so a large amount of their resources will go down that route. They are going for mandatory, what they have to do.”

Dr Sat Jassal, oral evidence session two

47. In England, healthcare is planned, funded and monitored (a process known as “commissioning”) by NHS organisations called clinical commissioning groups (CCGs). Because social care is commissioned by England’s 152 upper-tier local authorities, they also have a crucial part to play in making sure children life-limiting conditions and their families get the lifeline care they need.
48. There are some good examples of where CCGs and local authorities are commissioning palliative care which meets the needs and wishes of children and their families. As Lindsey Barron described in her oral evidence during session four, NHS Luton CCG and Luton Borough Council jointly commission children’s palliative care in an integrated way through a pooled budget. This includes a service level agreement for overnight short breaks at a local children’s hospice, in addition to a contract care service to provide short breaks within a family setting.
49. Luton CCG, Luton Borough Council, Luton & Dunstable University Hospital, Keech Hospice and a local children’s charity have all collaborated to produce a local palliative care strategy for children and young people²². Its overall aims are to:
- a. develop timely, flexible and responsive child and family centred palliative care services
 - b. strengthen universal services so that generalists can support children and families appropriately
 - c. build upon strengthening and further developing the current multi-disciplinary model of specialist palliative care.
50. As a further example, the Birmingham STP includes palliative and end of life care in the scope of its section on community care for children and young people²³.
51. More widely, however, the way in which children’s palliative care is commissioned is a significant barrier preventing families from making the choices they wish to about their child’s care. Research by Together for Short Lives²⁴ shows that families face a postcode lottery of support across England and that many families cannot access the community children’s palliative care they need out of hours and at weekends – caring for these children is not a 9 to 5 job.

52. Together for Short Lives' research found that commissioners are failing to assess the numbers and needs of children with life-limiting and life-threatening conditions, which is essential to ensuring that the correct services are commissioned to support them. It found that fewer than half (43%) of CCGs and just 23% of local authorities assess the numbers and needs of children who need palliative care. Despite 43% of CCGs claiming that they do this, only 4% of CCGs can say how many children with life-limiting and life-threatening conditions there were in their area, while only 2% of local authorities can provide this figure.
53. Almost half (46%) of CCGs are failing to implement the government's end of life care choice commitment and have no plans to do so. Only a third (35%) of CCGs responded that they are implementing this guidance, while a further 19% stated that their plans to do so are in development.
54. Fewer than a third (31%) of CCGs stated that they are currently implementing the NICE guideline on 'End of life care for infants, children and young people with life-limiting conditions: planning and management'¹. A further 27% stated that their plans to implement this guidance are 'in development'. Of concern, only 29% of CCGs commission services that can provide a paediatric palliative care multi-disciplinary team that meets the requirements of the guidance.
55. Together for Short Lives' research also found a major discrepancy between services commissioned between 8am and 6:30pm Monday-Friday and services commissioned to provide care out of hours. 93% of CCGs commission community children's nursing teams, but just 67% commission them to provide care out of hours. Although 64% of CCGs commission services to provide community paediatricians, only 29% commission them to provide out of hours care. Similarly, 95% of CCGs commission equipment services, including wheelchairs, but just 52% ensure that this support is available out of hours.
56. Many local authorities are failing to commission short breaks for children who need palliative care, despite being legally obliged to do so²⁵. More than one in five (21%) local authorities are failing to meet their legal duty to commission short breaks for disabled children with life-limiting and life-threatening conditions. This figure has worsened in the past year; one in seven (14%) local authorities were failing to commission short breaks for these children in 2016.
57. We have heard that poor commissioning is often caused by CCGs and local authorities being confused about which elements of children's palliative care they are responsible for commissioning, most typically short breaks for children with complex health needs. This is reflected in Lindsey Barron's oral evidence.
58. We have also heard that poor commissioning can be caused by a lack of clear guidance from government and NHS England and too little activity to oversee and hold CCGs and local authorities to account for the way in which they commission children's palliative care.



59. There is a postcode lottery of bereavement care across England for parents whose child has died. Nearly one in five (17%) CCGs do not commission this support and nearly half (45%) do not commission this support out of hours. Local authorities are also failing to commission this support – just 28% do so, while 18% can provide this out of hours.
60. CCGs and local authorities are failing to fund voluntary sector children's palliative care organisations – including children's hospices. Nearly a quarter (22%) of CCGs do not commission these organisations, despite the crucial role they play in providing support for children with life-limiting and life-threatening conditions and their families. Nearly three quarters (72%) of local authorities do not commission these services.
61. Too many areas still do not commission age and developmentally appropriate services for young people with life-limiting and life-threatening conditions. Young people have specific palliative care needs which differ from both younger children and older adults. Despite this, one in six (16%) CCGs are not commissioning age and developmentally appropriate services. Furthermore, a similar proportion (15%) of CCGs do not take steps to ensure that these young people experience smooth transitions from children's to adult palliative care services.
62. Despite significant challenges across England, there are still some examples of commissioners reporting a broad range of children's palliative care commissioning. The proportion of CCGs that commission short breaks, step-down care, and out of hours equipment services has risen since Together for Short Lives' research in 2016. The proportion of local authorities that stated they commission palliative care doubled, from 19% in 2016 to 38% in 2017. It is not clear, however, how much commissioners spent commissioning these services or whether it was enough to meet need.
63. In their written evidence, the Rainbow Trust said that there are few incentives for local commissioners to fund their services, despite the benefits that such support can bring to children, families and wider society. As Rainbow Trust set out in their Hidden Savings report in 2017, the savings that our service enables for the health and social care system are conservatively estimated at £2 million each year²⁶.
64. In their written evidence, the East of England Children and Young People Palliative Care Forum identify that certain palliative care strategies are lacking across the region, which leads to inconsistency and a lack of confidence. Specifically, the forum mentioned a lack of formal structures in place to identify and commission palliative care services that are required and a lack of awareness about what tools are available to assist effective palliative care processes²⁷.
65. East Anglia Children's Hospices (EACH) reported that there seems to be a lack of joined-up commissioning for children's palliative care across CCGs, STP areas and local authorities which EACH suggests is detrimental to children and families being able to realise their choices. The MCN principle and approach of collaboration, partnership and joined-up delivery across a wider area than just one CCG or one STP area enhances choice because of the issue of the relatively small numbers of children and the resultant need to consider economies of scale. EACH suggests that formalising and systematising MCNs is an opportunity to both improve the quality of service delivery and to enhance informed choice for child and family²⁸.

Statutory funding

66. The way in which children's palliative care is funded by the state in England is a further barrier to choice.
67. Together for Short Lives estimates that the cost of providing palliative care to children and young people amounts to hundreds of millions of pounds a year across the UK. The majority of children's palliative care is funded by organisations spanning the voluntary sector, the NHS and local government.
68. Voluntary providers, including children's hospices, help to ease pressure on the NHS. Children's hospices, for example, make a crucial contribution to local health economies²⁹:
- 92% of children's hospice charities provided end of life care to children and young people in 2015/16
 - 89% provided care which helped children manage their complex symptoms
 - 75% provided step-down care.

69. Without children's hospices, this clinical care would otherwise have to be provided and paid for in its entirety by the NHS.
70. Together for Short Lives reports that the state funding for charities delivering children's palliative care in England is patchy and declining year on year³⁰. It states that:
- cuts and freezes in statutory funding for children's hospice and palliative care charities means a bleak outlook for seriously ill children and families in England. This is despite the cost of delivering this care increasing by 10% due to additional demand
 - on average, the overall amount of statutory funding for charities providing children's palliative care continues to be on a downward trajectory, falling year on year (22% in 2015/16 compared to 23% in 2014/15 and 27% in 2013/14)
 - when taking the NHS children's hospice grant and funding from CCGs and local authorities into account, there was a wide range in the state's contributions to VCS children's palliative care providers' charitable costs in 2015/16. The maximum contribution received by a charity in 2015/16 was over half (53%). The lowest was 2%. 30% of charities received a contribution of between 21% and 30%. 30% of organisations received between 11% and 20%
 - the mean funding given to each charity by local authorities fell by 61% between 2014/15 and 2015/16. This means that local authorities are only contributing 1% of the money charities need to deliver children's palliative care. This means that, on average, local authorities contributed just 1% to the charitable costs incurred by charities in 2015/16, a fall compared to the 3% reported in 2014/15.
71. The Disabled Children's Partnership (DCP) have gathered increasing evidence of cuts to services for disabled children, including those with life-limiting conditions, and their families. A 2015 report³¹ found that a majority (58%) of local authorities cut spending on short breaks between 2011/12 and 2015/16. This trend is continuing and our members are seeing 'cost-shifting' between the health services and social care, with children and families falling between the cracks.
72. In November 2017, the DCP commissioned research by Development Economics to quantify what the current funding gap is for disabled children's services. These services include specialist equipment, speech therapy and short breaks. The DCP concluded that an estimated additional £433.9 million needs to be allocated to disabled children's social care services by local authorities and £1.1 billion by the NHS³².
73. We note the DCP is therefore calling on central government to pledge £1.5 billion a year to a disabled children's fund to plug the current funding gap. This equates to 0.2% of total government spending.

"The reality is that the level of cuts that government have made to...councils has absolutely crippled social care. Parents fight tooth and nail for every little thing that they need. From a commissioning point of view, commissioners are absolutely broke, so even providing simple things has become incredibly difficult...It's not because social services aren't wanting to help, it's because they don't have the resources."

Dr Sat Jassal, oral evidence session two

74. Together for Short Lives reports that, on average, adult hospices in England receive 33% of their funding from statutory sources³⁰. We note that the Scottish Government recently committed £30million over five years to Children's Hospice Association Scotland; this amounts to approximately 50% of their agreed charitable costs.
75. Between November 2016 and January 2017, Together for Short Lives consulted children's hospice charities in England on a potential new future formula for allocating the Children's Hospice Grant. This is allocated annually to all children's hospices in England. The total grant amount has increased incrementally from £8,829,180 in 2006/07 (part of £27million awarded over three years) to £11,000,000 in 2015/16. We consulted all current recipients of the grant on behalf of NHS England, which is responsible for administering the grant.

76. The value of the Children's Hospice Grant has not kept pace with the growing cost of providing clinical palliative care incurred by children's hospice charities. In 2006/07, the grant contributed an average of 14% towards the cost of providing clinical care in children's hospices. In 2015/16, when it had risen to £11,000,000, it contributed an average of just 8%.
77. In 2006/07, the grant contributed an average of £1,129 per child cared for by a children's hospice charity. In 2015/16, that had fallen to £947 per child. This was a fall of £182.65 (16%) per child.
78. We call on the government to bring about parity of funding in the state's percentage contribution to the charitable costs incurred by children's and adult hospice and palliative care charities. This would mean that children's organisations would receive at least 33% of their charitable costs, comprising contributions from NHS England, CCGs and local authorities. We note that the Scottish Government has committed to bring about parity and fund 50% of the agreed charitable costs of Children's Hospices Across Scotland.
79. We believe that the amount of funding available through the children's hospice grant should reflect the increase in demand, costs and complexity of care needed by children and young people with life-limiting or life-threatening conditions. We echo Together for Short Lives in recommending that the grant is increased in value to £25 million per year. This is based on a 14% contribution to the current cost of the clinical care provided by children's hospices, which is equal to the contribution originally made by the Department of Health when the grant was first awarded in 2006/07. The uplift also recognises any additional costs in developing reporting mechanisms and new services to meet growing demand.
80. We call on the UK's governments to invest in seed funding for voluntary sector organisations to set up age-appropriate services for young people transitioning from children's to adult services. Without these services, young people with life-limiting conditions will have no alternative to unplanned admissions to hospital if their health deteriorates. This will lead to poorer outcomes and unnecessarily higher costs to the state.

Workforce

81. Alexander Devine Children's Hospice Service has identified that, while progress has been made, there are still serious gaps in workforce that are preventing ready access to services. They highlighted children's community nurses, children's palliative care nurses and specialist nurses, while also acknowledging a lack of out of hours support³³.



82. The evidence we have gathered suggests that there are too few professionals who have the skills, knowledge and experience to meet the needs and wishes of children and families.
83. The Royal College of Paediatrics and Child Health's (RCPCH) PPM College Specialist Advisory Committee (PPM CSAC) states that children's palliative care is one of the newest medical sub specialities³⁴, having been established in 2007. RCPCH states that there are currently 14 children's palliative care consultants in the UK and several paediatric consultants who practice with an interest in palliative care. There are many regions in the UK with no access to children's palliative medicine specialists. Many single-handed consultants have no cover for leave or sickness and 'reprieve' from service requirement can be very challenging.
84. RCPCH reports that children's palliative care specialists are very concerned about untrained, self-nominated paediatricians taking on the 'lead' for palliative care services without having key capabilities in place. It states that a lack of access to fully trained specialists for advice and support is resulting in some poor practice.
85. During the third oral evidence session, Dr Simon Clark, Officer for Workforce Planning at RCPCH, made a conservative estimate that between 40-60 children's palliative care consultants were needed in the UK. This suggests a significant deficit of 26-46 consultants.
86. In its written evidence submission, the Royal College of Nursing (RCN) states that there is a growing body of evidence to show the children's palliative care workforce is limited. This is both in numbers of available children's nurses and care assistants and their capacity to provide the care required. It cites the following factors:
- As in other areas of nursing, more children's nurses are leaving the profession than joining it³⁵
 - Applications for 2018 entry to nursing education courses are now open and have already fallen by 13% compared to the same time last year, a total fall of 33% since the same time in January 2016³⁶
 - A paucity of education, learning and development opportunities specific to children's palliative care which is hindering local access to training. RCN believes that this is due in large part to budgets for continuous professional development for nurses being cut by 60% from £205m in 2015/16³⁷
 - The lack of an established or recognised core curriculum standard for what is needed at undergraduate and post graduate levels for children's palliative care
 - Despite e-learning opportunities expanding, this form of education and development – while useful for acquiring some elements of skill and knowledge – does not provide for opportunity to develop and hone excellent communication skills. RCN states that these are essential for all areas of nursing, especially children's palliative care
 - RCN states that members of its children's palliative care specialist interest group can cite many instances where advance care planning has not happened because professionals have shied away from what they have perceived to be a challenging or difficult conversation.
 - A lack of appropriate levels of training for all staff contributes to the general paediatric workforce's lack of understanding about children's palliative care. RCN states that this is demonstrated through late referrals, professional gatekeeping and lack of timely and appropriate communication and information for children and families.
87. RCN states that hospital specialist nurses are often restricted to working only in hospitals. This limits what care and support the statutory sector can provide for children who are spending more of their time living with their condition outside of hospital. This can place a greater demand on voluntary sector organisations such as children's hospices to fill gaps in care and support.
88. Amid a lack of formal systems, RCN suggests that commissioners and providers are relying too much on the initiative of individuals to make sure that statutory and voluntary organisations collaborate over larger geographical areas. It says that this is making children's palliative care vulnerable to other, more demanding priorities of NHS Trusts, threatening the ability of children and families to make informed choices.
89. From a survey of children's hospice organisations in the UK which Together for Short Lives undertook in 2016³⁸, we understand that:

- the nurse vacancy rate among children’s hospice organisations is equal to that of the NHS in England. The average vacancy rate was this year found to be over 11%, an increase on 2015’s findings of 10%. This represents over 130 whole time equivalent (WTE) posts unfilled
 - there is an increasing shortage of experienced nurses in children’s hospice organisations. In 2016, the number of vacancies was highest at a salary equivalent to Band 6 compared to salaries equivalent to Bands 5 and 7. In 2015, the highest number of average WTE vacancies were in Band 5
 - there is a lack of skilled nurses available to fill posts. More than half (61%) of children’s hospice organisations cited a lack of available appropriately skilled nurses being available to fill posts – similar to the 65% which reported this in December 2015
 - it is getting harder for children’s hospice organisations to fill nursing posts. Nearly two thirds (65%) of vacancies are described as hard to fill (vacant for over three months). This is greater than the 57% reported in 2015.
90. The RCN recommends that for an average-sized district, with a child population of 50,000, a minimum of 20 WTE community children’s nurses are required to provide a holistic community children’s nursing service³⁹. The Office of National Statistics estimates that there are 13,770,873 children aged 0-18 in England⁴⁰. If the RCN recommendation were to be met, this would require approximately 5,508 community children’s nurses. There were just 541 community children’s nurses in England in March 2018⁴¹.
91. These shortages are forcing children’s hospice organisations to cut back the palliative care they can offer to children and families. A majority of organisations (58%) now state that vacancies are having a negative impact on care – including a reduced offer to families or reduced short breaks offer. This is greater than the 43% of children’s hospice organisations which reported this in 2015. Nearly one fifth (17%) stated that they were being forced to close beds. Three (13%) services reported that vacancies affected their ability to provide 24/7 care, making 2016 the first year that this was specifically mentioned.
92. In its written evidence, the Royal College of Paediatrics and Child Health’s (RCPCH) Paediatric Palliative Medicine College Specialist Advisory Committee (PPM CSAC) state that there is a lack of community children’s nurses able to support complex and end of life care. Additionally, it suggests that many children’s hospices are unable to support medically complex care. This significantly affects the way in which highly complex care in the community can be provided, which in turn is increasing demand for unplanned care, increasing hospital admissions and delaying discharges from hospital⁴².
93. In her written evidence, Caroline Blurton (Childrens Community Nursing Service SSOTP NHS Trust) stated that local risk assessments can mean they are unable to offer, or must withdraw their offer, due to risks associated with lone working. She also said that children that are diagnosed at tertiary centres outside our area are not always aware of her service’s offer.
94. Young people’s attitudes to death and dying are cited as a barrier to attracting nurses to work in children’s palliative care. In her oral evidence, Rachel Cooke (Bereavement Service Manager and Joint Manager, Child Death Helpline, Great Ormond Street Hospital Foundation Trust) suggested that young people are more fearful of children dying. She stated that younger professionals are more affected by children dying than their older colleagues because child death has become less prevalent in recent decades.



4

The opportunities for improving the extent to which children and families can make these choices



Developing personalised palliative care for children and young people

In the end of life care choice commitment, the government states: “We will put in place measures to ensure everyone’s preferences are recorded and shared digitally. We will look to expand the availability of options for greater personalisation and control at the end of life enabling more people to decide how money should be spent to meet their needs. We will explore the potential for care coordinators at the end of life. We will pilot a new way of planning care which links up long-term conditions management with end of life care, through “serious illness conversations”. We will ensure progress on personalisation can be tracked by developing new measures of success for personalisation.”

95. In its written evidence to our inquiry, NHS England states that giving people of all ages more choice and control through the personalisation of care and support underpins the vision for end of life care⁴³. It states that personalised care can be defined as people having the knowledge, skills and confidence to exercise choice and control over decisions that affect their own health and wellbeing (including personalised care planning and shared decision making).

96. Through its audit of the extent to which the NICE guideline is being implemented¹¹, Together for Short Lives has found that, across England, this is mixed:

- Children, young people and their families sometimes have an advance care plan or equivalent.
- Children, young people and their families sometimes have a care plan which address the care and support needs of all immediate family members.
- Professionals mostly or usually think about how best to communicate with each child or young person and their parents or carers.
- Services within all relevant agencies sometimes engage in planning for the specific needs of the child/young person.
- Children, young people and their families sometimes have easy access to information about their condition and services available to them.
- In some areas, processes are in place for families to discuss their preferences for organ and tissue donation.

97. During our oral evidence sessions, we asked young people with life-limiting conditions, families and services if professionals are having honest discussions with children and their families about their conditions and the fact that they are life-limiting or life-threatening. We also asked how well these conversations were being conducted. Again, we found a mixed picture:

“Initially, we didn’t realise my condition was going to shorten my lifespan and I think for a long time people skirted around that conversation. It came to a head and my consultant sat down on a bed next to me in the hospital when he just told me, but in a very compassionate way and in a lot of detail. My hospice nurse from The J’s – she’s had so many conversations with me over the years and nothing is off-limits. She doesn’t lead the conversation, she just guides me through it, so we’ve always had very open and honest discussions and I think that’s reflected with all our professionals. We are open and honest on both sides.”

Lucy Watts MBE, oral evidence session one

“I’ve had quite a lot of involvement over the last few years in post working with professionals related to developing emergency healthcare plans. On the family experience, a lot of families don’t have early discussions, maybe because they’ve got lots of different consultants involved. It may be because perhaps the professionals aren’t sure how to approach it with the families, and very much when we’re doing the emergency healthcare plans I’ve found that it’s very varied with what skills the doctors and nurses have in how they relay the information. Sometimes there’s lots of medical jargon the families don’t quite understand. They’ll talk about resuscitation and different levels that the family don’t really know what they’re signing up for. I think that the conversations aren’t necessarily always open and honest because the families aren’t quite on the same page as the doctors and they don’t understand what they’re saying. A lot of families have said through their journey they’ve not had those open conversations early enough. I think if we’re talking about life-limiting, life-threatening conditions, it’s a difficult conversation to have, so sometimes it’s not broached with the families when it should be.”

Julie Potts, oral evidence session two

“We have a very positive experience if the family wish to engage in that conversation. Once you’ve got that engagement, we all talk to the family, be it parents and the child, depending on the age of the child and their ability, wanting to join in that conversation, and we’ll formulate what we call a wishes document, an advanced care plan by another name, and once that’s done, it’s not a legal document, it’s not set in stone. It’s a fluid document, it can be changing all the time, so it’s important it gets that review. Where we are in the South West, we cover the whole of the South West, South Wales, so all those care plans are shared electronically to all the people that are involved in that child’s care. It’s the responsibility of the person that updates that document then to share it back with all those contacts, so you’ve got a live document. So if a child comes into the Children’s Hospital in Bristol, I will get an alert on my computer to say this child has come in and they’ve got a wishes document, so that we can go and see that..”

Francis Edwards, oral evidence session two

“I don’t doubt that it’s really difficult all those families. Once, I had a member of the nursing staff in a room with me and I thought I had been quite clear about what was going on, what the risks were, being as sensitive and as supportive as you can. Then the family went back into the intensive care area and the nursing staff then listened to them talking on the telephone. What they said was virtually the opposite of what I think I’ve said. Now I’m not saying that happens all the time, but I think there’s an element of actually where this information is overwhelming

Dr Simon Clark, oral evidence session three

98. Some of the evidence we received suggests that some professionals feel ill-equipped to handle conversations about advance care planning. Coventry and Warwickshire Children and Young People’s Palliative Care Services¹² say it can be very difficult to have these discussions if the team caring for the child has not received appropriate training and do not feel they can have these sensitive conversations.

99. We also asked witnesses about how effective they feel their plans are:

“In terms of actually having the care plan, it’s really useful because it’s all in one place and actually you can share the same care plan to any kind of professional you encounter. You can send it to the continuing healthcare team or social services or a consultant or if I’m going to be admitted to hospital you can send it to them. So actually, everyone knows where they stand. I have had to fight for my wishes, I won’t deny that, there have been times when they have wanted to put me in hospital when I haven’t wanted to be there, but actually we have always been able to come to a mutual agreement. For example, if I need intravenous antibiotics if I can have them at home so I am at home rather than hospital. It’s more of a conversation starter. I can say, these are my wishes, what can we do, and get agreement on those terms.”

Lucy Watts MBE, oral evidence session one

100. During our first oral evidence session, Junior Jimoh, a young man with a life-limiting condition, told us that he had been supported in developing care plan. However, he told us that he felt the professionals caring for him were not following it. He reported that different carers whom he did not know would be sent to his home to care for him without him having prior notice.
101. Junior also told us that he had been supported in developing an end of life care plan, but it was unfinished and he did not know what status it had.
102. Shockingly, Junior told us that some professionals fell asleep while they were caring for him at night. In other instances, providers would offer nurses that did not have the skills required to care for his tracheotomy.
103. In its written evidence, NHS England states that one way of achieving greater choice and control is through personal health budgets (PHBs). In 2017/18, NHS England worked with five local areas to test how PHBs would work within end of life care.

“We have to ask the question: who is this plan for? Is it for professionals or is it for the family? There is a bit of work that has been going on nationally about trying to create a document that can be used all over the country. That has come to a place where that’s massive because intensivists want this kind of information and palliative care (services) want this information.”

Francis Edwards, oral evidence session two

104. We note the positive early findings from this work; however, we remain concerned about a lack of evidence of testing PHBs for children with life-limiting conditions in these pilots. We do welcome evidence from NHS England which states that wider use of PHBs and integrated personal budgets that span health, education and care indicate that the benefits seen for children and their families are similar.
105. We believe that personal budgets can provide greater choice and control for young people and families of children with life-limiting conditions. However, there are a series of barriers identified by Together for Short Lives⁴⁴ which we ask the government and NHS England to address to offer greater choice and control to children and families:
- a regional disparity in the knowledge of personal budgets amongst commissioners
 - the difficulties that CCGs face in disaggregating existing contracts with providers
 - the need for commissioners to recognise that parents often have the best understanding of their children’s needs – but require support to meet their needs
 - the need for those commissioning personal budgets to understand how vital non-clinical assistance can be, allowing for sufficient provision within children’s personal budgets
 - high staff turnover within CCGs, which can lead to a frequent loss of knowledge and expertise
 - families and young people are often frustrated at the length of time it takes for personal budgets to be set up.
106. Together for Short Lives has also identified distinct challenges presented to the voluntary care sector (VCS)⁴⁴ which will need to be mitigated to make sure that children with personal budgets are able to access sustainable services:
- VCS providers have little experience in marketing their services – therefore it will be important for guidance and assistance to be made available
 - VCS providers and commissioners must have a close relationship to ensure accurate estimates of the cost of services
 - It is often difficult for VCS providers to determine their ‘local area’, resulting in interaction with multiple CCGs, who all have distinct processes, so a degree of regional standardisation utilising STPs may be beneficial.

107. Services like Rainbow Trust prioritise families according to their need and not by their ability to pay. They are concerned that, if a family knows that their service is free at the point at which they need it, they would question why they needed to use their budget on buying services from them.
108. Personal budgets can be held by commissioners, by brokers or third parties – or by families through the means of direct payments. We believe that direct payments can provide greater choice and control for parents. However, we note that some families do not wish to access direct payments because of the administrative work and added responsibilities they entail. These can include recruiting appropriate carers, managing staff absence and sickness and other human resource (HR) functions which commissioners would otherwise be responsible for. It is also vital that young people and their families understand what their responsibilities are as part of receiving direct payments as many have found it unclear, resulting in them having to make up their own rules up to a point. We would welcome the opportunity to work in partnership with the government and NHS England to mitigate these challenges.
109. It is equally important for those receiving personal budgets through direct payments to understand how to separate business and care relationships. VCS providers have found that negotiations over the purchasing of care services has strained the care relationship with families, especially when they become protracted. We would welcome working in partnership with NHS England and the government to develop workshops to provide guidance and understanding for both sides.

(On personal budgets) “Yes, it will help providing we have the service out there to deliver the care. A personal budget is only as good as the services you’ve got.”

Lindsey Barron, oral evidence session four

110. We believe that all 40,000 babies, children and young people in England with life-limiting or life-threatening conditions should have the right to an integrated assessment, plan and personal budget – if they would like one.
111. However, we believe that Integrated Personal Commissioning and/or personal health budgets are not the only means by which the government seeks to improve the choice and control which people of all ages have over their palliative and end of life care; for choice to be realised. The NHS and local authorities have an important role to play in commissioning care across a range of settings, including hospitals, hospices and in the community.
112. We also believe that the government and NHS England should do more to help families, professionals and provider organisations to adapt to personal budgets. We believe they could:
- facilitate workshops and training sessions involving commissioners, care providers and other related professionals to share best practice and to foster an understanding of complex care needs amongst those commissioning personal budgets
 - offer training to families receiving personal budgets as direct payments
 - provide or fund training, a helpline and/or website to provide up-to-date information for families, professionals, services and commissioners; these should aim to improve the extent to which they understand personal budgets and better support families receiving direct payments to manage payroll and HR responsibilities and to understand how to separate business and care relationships. It would also be an excellent opportunity to foster understanding between these groups.
 - better promote local offers and make resource allocation systems available to families of those receiving personal budgets, so they are aware of the support available to them
 - reduce the length of time it takes for personal budgets to be set up.

Improving care quality across all settings

In the end of life care choice commitment, the government says: “We will ensure end of life care is part of all the major programmes to transform the NHS, including in the development of local plans and the focus on urgent and emergency care and seven-day services in hospitals. Working with our partners, we will continue to improve hospital care through the Transforming End of Life Care in Hospitals programme and ensure that the Care Quality Commission continues to focus on end of life care in all settings where it is delivered. We will develop urgent care clinical advisory hubs to improve access to urgent clinical advice and support for end of life care, including expert advice from specialist palliative care services. We will explore improvements in end of life care for care home residents and implement new ways of delivering effective end of life care in community settings. We will work with our partners to address inequality and variation of access to end of life care services.”

113. We welcome the government’s emphasis on making sure that the Care Quality Commission (CQC) focusses on end of life care in all settings where it is delivered. We note that the CQC has streamlined its assessment frameworks and placed children’s hospices within the hospital framework. CQC has produced sector-specific guidance for those inspecting hospices for children and young people.
114. We also welcome the fact that the CQC’s key lines of enquiry, prompts and ratings characteristics for healthcare services⁴⁵ state that inspectors should assess the extent to which services are delivered and coordinated to ensure people who may be approaching the end of their life are identified, and that this information is shared.
115. We call on CQC to make sure that its new approach to regulation brings about a consistent system for inspecting children’s palliative care services, regardless of the setting in which it is provided.
116. We also call on CQC to make sure that it can assess the way in which networks of providers offer joined-up care to children and young people with life-limiting conditions. This should include managed clinical networks.

Identifying and spreading innovation

In the end of life care choice commitment, the government says: “NHS England will lead on identifying, adapting, promoting and sharing effective models of end of life care for dying people, including lessons from innovative ‘Vanguard’ sites and new models of care. We will conduct a series of roadshows to exhibit effective approaches and establish a central website as a shared knowledge resource for all.”

117. We welcome the various actions that NHS England is taking to identify, adapt, promote and share examples of innovation in children’s palliative care.
118. For example, we welcome the fact that the [National Institute of Health and Care Excellence \(NICE\) published a resource impact template alongside the guideline on end of life care for infants, children and young people](#). This tool allows local areas to input their population data and it calculates the overall cost and savings of implementing the new guidelines. Using the total population of children in England, NICE calculate that by investing £12.7million in implementing the guidance, **non-cash savings worth £34.7million** would be released back into the NHS in England.⁵
119. Because there are relatively few children with life-limiting conditions, children’s palliative care is often not prioritised by CCGs and local authorities. STPs and ICSs offer an important opportunity to commission children’s palliative care on a greater scale which involves children’s palliative care networks. However, we feel that too little is currently being done to test approaches to planning, funding and providing children’s palliative in STPs and ICSs.
120. We call on NHS England to develop service specifications for children’s palliative care, which span generalist to specialised care provided in a range of settings.

121. We call on NHS England to make sure that approaches to commissioning children's palliative care are tested by STPs and ICSs.
122. We call on NHS England, STPs, ICSs, CCGs and local authorities and provider organisations to do more to collect and share examples of good practice in commissioning and providing children's palliative care.

Leadership

In the end of life care choice commitment, the government says: "Working through our commitment to end of life care in the Mandate to the NHS, we will promote and support the Ambitions for Palliative and End of Life Care Framework. We will also engage with clinical commissioning groups and Health and Wellbeing Boards on improving end of life care provision through local strategic planning and commissioning. We will provide commissioners with data, tools and palliative care currencies to help identify palliative care needs in local areas and the best ways to commission services to meet those needs."

123. In its mandate to the NHS⁴⁶, the government aspires to increase the percentage of people identified as likely to be in their last year of life, so that their end of life care can be improved by personalising it according to their needs and preferences (page 16).
124. We are concerned, however, that this will not include all 40,000 babies, children and young people in England with life-limiting or life-threatening conditions: not all children who need palliative care are in their last year of life. It is also challenging to identify children in their last year of life because life-limiting conditions in children are highly unpredictable.
125. More widely, we are concerned that, outside of tackling obesity and poor mental health, the government has not set any priorities for improving children's health in its mandate to NHS England.
126. We believe that the 10-year plan the government has asked NHS England to develop presents an important opportunity to specify that meeting the end of life care choice commitment should be a priority for commissioners and providers.
127. We call on the government to specify in its mandate to NHS England that the end of life care choice commitment be implemented in full for babies, children and young people. This should also be reflected in the NHS England's forthcoming 10-year plan.
128. More widely, the government should specify in the mandate that health services for babies, children and young people with long-term disabilities are commissioned, resourced and provided. This should also be reflected in the NHS England's forthcoming 10-year plan.
129. NHS England also states that it has developed and published [a children's palliative care funding currency](#). In simple terms, this is a formula which describes for local planners and funders of healthcare (known as clinical commissioning groups, or CCGs) how the cost of providing children's palliative care varies, depending on a number of factors. The currency provides official recognition that the NHS has a role in funding children's palliative care in England and could help CCGs to better understand their responsibilities for supporting these vital services. The guide also usefully includes:
- details of the currency formula model and how it helps commissioners to pay for local children's palliative care services
 - the data needed to use the currency formulas
 - an Excel template to help collect data
 - tools to support providers to collect and validate data
 - advice on sharing information with commissioners.

130. The guide also recommends that while bereavement counselling does not form part of the currency model, commissioners should think about the excellent value that these services provide when they commission services.
131. We welcome the guide. However, we are concerned that CCGs should not be forced to implement the new currency or the guide. There are also a number of important omissions from the guide, including:
- how progress on achieving the objectives of the currency will be measured
 - how non-clinical elements of children’s palliative care, such as short breaks, will be funded
 - how voluntary sector providers can be supported to implement the systems they will need to collect data to make the new approach work.
132. We also note that Together for Short Lives reported that in 2016, only a small minority (22%) of charities had been approached by their CCGs to discuss it. Nearly two thirds (63%) had not been spoken to by their CCG about the currency at all. Together for Short Lives still has no evidence that any VCS children’s palliative care providers in England are being funded by CCGs using the currency.

(When asked about the currency) “I can’t tell you very much about that. (Luton) CCG opted not to participate in the initial pilot...we haven’t looked at the currency, haven’t used the currency. We are working with a very fixed budget on one provider and there’s not been much wiggle room. I have read through the currency documentation a few times: personally, I find it very confusing.”

Lindsey Barron, oral evidence session four

133. We call on CCGs and local authorities to implement the existing policy framework which describes how children’s palliative care services should be planned, funded and provided. This includes:
- the government’s end of life care choice commitment for children
 - the NICE guideline¹ and quality standard⁴ on end of life care for children
 - the Ambitions for Palliative and End of Life Care Framework
 - Together for Short Lives’ guide to jointly commissioning palliative care for children and young people aged 0-25
 - Together for Short Lives’s Core Care Pathway⁴⁷.
134. We call on health and social care commissioners to make sure that families can access care and support around the clock. CCGs and local authorities should recognise the importance of out of hours support for families who have a child with a life-limiting or life-threatening condition and commission services accordingly. Many of these families care for their child 24/7 and need out of hours support from community children’s nurses, community paediatricians, equipment services and others.
135. We call on CCGs and local authorities to adopt the recommendations of the NICE guideline¹. In particular, commissioners should support the development of managed clinical networks, as has happened in Wales, which will help the planning and commissioning of services to meet the needs of children and families.
136. We call on the government and NHS England to provide clarity over responsibilities and guide commissioners on how to apply new models of funding: the Secretaries of State for Health and Social Care and for Education and the chief executive of NHS England should urgently write to STPs, ICSs, CCGs and local authorities to make clear which parts of the health and care system in England are responsible for commissioning palliative care for children and young people aged 0-25. This communication should set out the difference between specialised and general children’s palliative care; it should describe those elements that NHS England is directly responsible for commissioning, and those that STPs, ICSs, CCGs and local authorities are responsible for.

137. We ask the government and NHS England to consider appropriate mechanisms to bridge the children's palliative care accountability gap. They should develop a system to monitor how CCGs and local authorities are supporting children's palliative care in accordance with their legal duties.
138. In its written evidence, NHS England cites two more initiatives which it states are helping to implement the choice commitment. These include work to establish a national data set for community services (the Community Services Dataset⁴⁸) and ongoing work to develop a needs and complexity-based currency for disabled children and young people's community healthcare.
139. The Community Services Dataset (CSDS) was launched in October 2017. NHS England states that it would be capable of collecting significant information on the care and outcomes delivered by palliative care services for children and young people. It is a mandatory data collection for all organisations that receive funding from the NHS to provide care.
140. NHS England state that the dataset needs further work to improve the way it is used, which Together for Short Lives is supporting. Children's hospices have yet to register or begin submitting data because, in order to submit data electronically, many children's hospices would need to divert some of their charitable funding to support work to develop and implement a digital information strategy. NHS England also say that many lack the technical expertise to manage this process. NHS Digital has not pressured hospices to submit data at this stage; therefore, there is currently no validated and comparable data for all specialist palliative care services.
141. We recognise the potential of the CSDS to better describe the activity that children's palliative care providers are undertaking and to make a stronger case to commissioners to plan and fund services which are providing children's palliative care. However, we note the significant resources that voluntary sector children's palliative care providers will need to invest in order to make sure they have the people and systems in place to record and share the CSDS data that NHS England and NHS Digital require. Without these additional resources, voluntary sector providers will be forced to fund work to implement CSDS using money which would otherwise have been spent on providing palliative care.
142. We call on NHS England to provide funding to voluntary sector children's palliative care providers so that they have the resources they need to begin recording and sharing the CSDS data.
143. We call on the government to undertake a review of the children's palliative care currently available to children with life-limiting conditions in England as a matter of urgency. This should lead to a cross-departmental children's palliative care strategy for achieving better outcomes for children and families.



The right people with the right knowledge and skills to deliver high quality personalised care

In the end of life care choice commitment, the government says: “We have agreed deliverables on improving end of life care education, training and workforce provision and planning with Health Education England (HEE). HEE will develop a refreshed competency framework for end of life care, implement a national action plan to promote good practice and work with its partners to review end of life care within undergraduate and postgraduate curricula. HEE will also include end of life care in its work to develop Community Education Provider Networks, and its work on the future of the nursing workforce. HEE will explicitly include end of life care in its wider workforce planning to deliver the NHS Five Year Forward View.”

144. We are concerned about the fact there are too few professionals with the skills, knowledge and experience needed to provide children’s palliative care in different settings, which could be due in part to the fact that the government has not set any priorities to rectify this in its mandate to Health Education England⁴⁹.
145. We call on the government to specify in its mandate to Health Education England that it should make sure that a health and care workforce in place in implement the end of life care choice commitment in full for babies, children and young people.
146. We are concerned that the recent changes in NHS pay, while welcome, may unintentionally further exacerbate challenges which voluntary sector children’s palliative care providers face when recruiting staff. Unlike other healthcare organisations, voluntary sector hospices will not be able to access the additional funding to meet the pay increases but will face considerable pressure to match the rises in order to remain competitive.
147. Hospice UK, Together for Short Lives and Marie Curie estimate that over the course of the proposed three-year pay deal, the additional costs incurred by voluntary sector hospices will be in the region of £50-60 million.
148. They are concerned that, without additional support, hospices will be faced with the difficult choice of whether to draw on charitable resources to fund the pay award or to reduce services. Given the challenging fundraising climate and the scale of the financial impact, we fear that the latter will be the more likely outcome. NHS hospices, in contrast, will have the additional costs met by the increased resources made available to their NHS trusts.
149. We note that, previously, the government has sought to mitigate the impact of changes in NHS employment terms and conditions for hospices. In 2004, when the employer contribution to the NHS pension scheme was increased from 7% to 14%, the government provided additional central funding for hospices, in recognition of the fact that hospices would otherwise have been at a significant disadvantage compared to NHS organisations. We ask that the government considers similar action in light of the NHS pay award.
150. We call on the government to provide funding to voluntary sector children’s palliative care providers to help them mitigate the impact of changes in NHS employment terms and conditions on their services.
151. We did not receive any evidence which suggest that HEE is assessing shortages in voluntary children’s palliative care sector medical or nursing workforce as part of its work to model the demand for professionals. We find this concerning.
152. While we welcome the competency framework for end of life care⁵⁰ which HEE commissioned and which Skills for Health and Skills for Care published in 2017, we are concerned that it only relates to care for adults who are likely to die within the next 12 months.
153. We call on Health Education England to develop a competency framework for providing children’s palliative care.

154. We note that HEE is working with NHS England and NHS Improvement colleagues to undertake a service led review into the way in which children's palliative care (level 2 and 3) is provided. HEE state this will take workforce issues into account, as well as considering work to develop resources and learning opportunities for a whole workforce, including non-medical and GPs. HEE say that the group will consider whether special interest modules, perhaps in partnership with RCPCH, could be developed into a multi-professional credential to target a workforce gap.
155. To meet the challenges of making sure that there enough professionals who have the skills, knowledge and experience to meet the needs and wishes of children and families, the RCPCH recommends the following across the UK:
- The existing workforce should be mapped to establish a baseline and service delivery assessed against required standards
 - General paediatric consultants with an interest in paediatric palliative care should be available in all paediatric centres as part of a formalised, commissioned managed clinical network
 - A strategic group of stake holders should develop clear service specifications (from secondary to specialist level) alongside an education and training plan for expanding the workforce
 - A robust process for training and assessing children's palliative care professionals should be developed. There is an urgent need to develop a training and education model that delivers a fit-for-purpose workforce, able to support the complex clinical care of children with life limiting conditions across the spectrum of paediatric practice, including in hospitals and critical care units and also in hospices and at home.
156. The revised RCPCH Progress curriculum in PPM (which RCPCH have submitted as written evidence to this inquiry) defines the capabilities of the specialist consultant in PPM². Learning outcomes include an expectation for regional leadership and service development.
157. In its written evidence³⁴, RCPCH states there are currently four training posts (GRID posts) for children's palliative care consultants across the UK. These are based in Leeds (Yorkshire and Humber), London (Great Ormond St Hospital, or GOSH) and Cardiff. GOSH was able to offer two posts in September 2018 to support GRID training, regional services must have more than one consultant. This restricts training sites and opportunities.
158. PPM special interest training (SPIN) was suspended in January 2017. This was due to:
- a lack of specific training posts
 - limited access to professionals who could supervise it
 - examples of poor practice.
159. RCPCH state that support was continued for the current (approximately seven) candidates to complete their SPIN training. The conclusion of the CSAC is that candidates are unable to achieve volume, depth and diversity required for supplemental training without access to clinical experience in a specialist centre. The CSAC have resumed work on determining SPIN capabilities and hope to complete this work by July 2018.
160. RCPCH is taking a range of actions to make sure that medical education for paediatricians includes children's palliative care. It is clear that PPM specialists should:
- work within competencies set out by RCPCH
 - work in a leadership and guidance framework supporting a regional service within an interdisciplinary team
 - maintain specialist on-call rotas
 - provide consultations, symptom management and end of life care in hospitals, homes and children's hospices

- plan complex care services
 - offer knowledge, lead and innovate as part of work to design services, undertake research, ensure patient safety and provide education and training
 - provide specialist advice and pastoral support to the wider healthcare team, including generalists with an interest in PPM.
161. RCPCH states that there is a clear need for more work to train and educate paediatric generalists with an interest in palliative care to meet specific areas of patient need. It states that these generalists should:
- provide care (including supporting continuity of care) for patients with multiple comorbidities, who depend on technology and who potentially have life-limiting illnesses
 - develop more doctors who can support more complex and dependent care in the community.
162. RCPCH states that PPM should be embedded in undergraduate training programs across the UK. It says that PPM is a core component of the curriculum for foundation and core training for all paediatricians.
163. RCPCH goes on to say that, at present, it is unclear how this standard is being met in areas without access to specialist PPM. GOSH and other centres offer 'taster days' to foundation and other doctors.
164. From a small sample (25%) of children's nursing degree courses which Together for Short Lives have obtained data about earlier in 2017³⁸, we understand that:
- a third (33%) of children's nursing degree courses are planning to increase the number of places which they offer to undergraduates
 - most, if not all, include some educating nurses about children's palliative care
 - most incorporate what we recognise as elements of good practice in children's palliative care education in their curricula
 - there are some significant gaps in the way in which undergraduate children's nurses are educated about children's palliative care:
 - one in five (20%) course leaders state that their students are unable to learn from parents and carers about what it is like to have a child with a life-limiting condition as part of their course
 - over a quarter (27%) stated that they had not devised children's palliative care competencies for their students
 - just over half (53%) stated that they are planning to further develop their children's palliative care education.
165. From a separate survey about funding for student placements in voluntary sector providers of children's palliative care conducted by Together for Short Lives in 2015⁵¹, we understand that:
- they play a vital role in educating the future nursing workforce in the UK: Together for Short Lives estimates that voluntary sector providers of children's palliative care offer placements to over 600 pre-registration nursing students every year
 - nearly two thirds (63%) of respondents cited the availability of mentors being the biggest challenge to providing these placements
 - if Together for Short Lives' sample represented all voluntary sector providers of children's palliative care in the UK, they estimate that 40% receive no funding for the placements they offer
 - these payments vary widely in their size, their origin and in the way in which they are calculated: of those voluntary sector providers of children's palliative care that are paid for providing placements, two thirds were paid directly from the universities themselves. The remaining third got their funding from Health Education England local education and training boards (LETBs).

“I think there is a big thing around education about professionals distinguishing between palliative care and end of life care morphed into one, and that changes the attitude of the conversation. There needs to be a national conversation around what we mean by children’s palliative care. I think that’s really, really important if we are to make any progress.”

Francis Edwards, oral evidence session two

166. During our fourth oral evidence session, Rachel Cooke (Bereavement Service Manager and Joint Manager, Child Death Helpline, Great Ormond Street Hospital Foundation Trust, representing the Royal College of Nursing) stated that cuts in budgets to continuing professional development (CPD) was a barrier to qualified professionals from having the knowledge and skills needed to care for children with life-limiting conditions.
167. We call on Health Education England and the Council of Deans of Health to work with the Royal College of Paediatrics and Child Health to develop a children’s palliative care training and education model. This should help deliver a workforce which has the skills, knowledge and experience needed to support the complex clinical care of children with life-limiting conditions across the spectrum of paediatric practice, including in hospitals, critical care units, hospices and at home. This should help make sure that all professionals – both specialist and general – who provide care for children with life-limiting conditions have the necessary skills and knowledge.
168. We call on the Council of Deans of Health to encourage university undergraduate nurse programmes to adopt the new Nursing and Midwifery Council (NMC) standards for nurses⁶, in addition to elements of recognised good practice in curricula for children’s palliative care nursing education set out by Together for Short Lives⁵².
169. We call on Health Education England to assess the demand for nurses from children’s hospice organisations and include it in their planning models. If it is found that there are too few children’s nurses likely to fill posts across all types of healthcare provider, we call on universities to increase the number of places they offer to undergraduates. The UK’s governments should recognise the importance of children’s hospice nursing by including these vacancies in the wider NHS nurse vacancy figures.
170. We call for children’s hospices to be reimbursed for the placements they provide to undergraduate nurses in a consistent and transparent way across the UK. This would help make sure that providers can maximise the number and quality of placements on offer. In England, we call for children’s hospices to be given access to the education and training tariffs determined annually by the Department of Health and Social Care.



171. We call on the government to make sure that the UK's exit from the European Union does not have an adverse impact on the supply of nurses available to children's hospices. We also ask ministers to put appropriate education and regulatory frameworks in place to make sure that providers can continue to recruit from other European countries.
172. We call on Health Education England to focus specifically on outlining career pathways and providing guidance for delivering outcomes-led education for children's palliative care nurses.

Working together with system partners and the voluntary sector to deliver the commitment

In the end of life care choice commitment, the government says: "We will continue to work closely with our voluntary sector partners including on specific projects to improve end of life care in hospital and out-of-hospital settings, promote a national conversation about death and dying and develop local volunteer networks."

173. During the course of our inquiry, we asked to what extent is the care and support which children receive from different professionals and organisations across health and social care joined-up.
174. Perhaps more so than for any other population group, joined-up care and support is crucial for children with life-limiting conditions and who need palliative care. We know from evidence that a disjointed system of care presents many challenges for families of children with life-limiting conditions. Because their conditions are often so complex, these families must typically liaise with around 30 different professionals from education, social care, health and other services.

"We've got four care plans...one for home, for our continuing care service. One for school and one for the community, when he goes on short breaks and working with social care. One in our hospice. If we put them all together to create a super care plan, it would be brilliant, but of course, we can't do that because health must have theirs, education must have theirs, and that's disappointing. We've been involved in writing all four of them and I just got great at cut and pasting, because I'm just giving them exactly the same information and just popping it into the forms. That's if you can get an electronic form off them. 'Can't do that. Data sharing.' Data sharing can get in the way, not only when you're working with one service, but across services. It is used as a vehicle to act as a barrier, rather than an enabler sometimes. Absolutely recognise Data Protection Act, etc, but sometimes that can be a challenge."

Doug Morris, oral evidence session one

175. All the evidence suggests that the best outcomes for children with life-limiting conditions and their families are achieved when there is effective partnership working between parents and services, with care co-ordinated around the needs of the family.
176. We know that joined-up care is possible from other evidence that we have heard. Bereaved parent Steph Nimmo described how one consultant, a neonatologist, asked her who favourite GP was. The consultant kept the GP up to date on her daughter's condition and helped to integrate her care. We welcome initiatives like the one currently being developed in Bristol, where providers in both the statutory and voluntary sector providers are working together to try to make sure that children have the option of receiving end of life care at home⁵³.
177. Sadly, we have heard that joined-up working is too often not the case. For example, Junior Jimoh, a young man with a life-limiting condition who provided us with oral evidence, told us that two consultants in charge of his care when there should only be one. He told us that professionals caring for him did not interact with each other, or made assumptions about his condition. He said that he was seen by his consultant once a year, and that he was not confident they were co-ordinating his care.

“The mistake is the total lack of co-ordination. We need to have better co-ordination of the services we have. Strong local networks are part of the answer to the issues we face. There are some good examples – the West Midlands being one. The commissioners should be (taking the lead on this)”

Francis Edwards, oral evidence session two

178. We support the aspirations of the special educational needs and disability (SEND) system in England; we believe it has great potential to join-up assessments, plans and services across education, health and social care for children with life-limiting conditions.
179. However, we are concerned that the government’s vision for the SEND system is not being realised for children with life-limiting conditions. We note that children with life-limiting conditions – and professionals and services who provide palliative care – feel that the changes to SEND support have not substantially or adequately changed as a result of the reforms.
180. Families say they feel frustrated by the system. They have said that frequently they are not consulted early enough in the process and that when they disagree with the education, health and care (EHC) plan it is difficult to make the required changes. There is inconsistency in the way rules are applied between different areas, with families and children with life-limiting conditions experiencing different levels of engagement in assessment. There still seems to be pressure on parents to bridge these gaps themselves.
181. Some within the voluntary children’s palliative care provider sector feel that EHC plans still do not contain enough insight from health and social care. They feel that, while some good assessments are being carried out, they are predominantly focused on educational need and do not reflect a holistic view of the young person’s need.
182. There appears to be geographical variation in the success of joint working. We are seeing patchy provision between geographical areas and many members mentioned social care as being particularly challenging to integrate.
183. CCGs and local authorities have a legal duty to jointly commission services for disabled children, including those with life-limiting conditions, under the Children and Families Act 2014. Section three of the *SEND Code of Practice*⁵⁴ sets out in detail what local areas must and should do to jointly commission services for children and young people aged 0-25 with special educational needs and disabilities (SEND).
184. Despite this, in response to a series of freedom of information (FOI) requests issued by Together for Short Lives in 2017⁵⁵, only 68% of CCGs reported that they commission services for children with life-limiting and life-threatening conditions jointly with their local authorities⁵⁵. Fewer than half (49%) of local authorities reported that they jointly commission these services with CCGs. Together for Short Lives has produced guidance for CCGs and local authorities on jointly commissioning palliative care for children and young people⁵⁵.
185. We are also concerned that local authorities are not meeting their statutory duty to assess the needs of parent carers (section 97 of the Children and Families Act).
186. The overall legal framework for health and social care for disabled children, including those with life-limiting conditions, is complex. It stems from more than ten different acts of Parliament, regulations and guidance which have developed over the past 50 years. While the 2014 Children and Families Act made important changes to the law which we welcome, it did not remove this complexity. The joint commissioning duties were intended to address this, by ensuring that arrangements are in place to resolve disputes between agencies. Instead, we are increasingly seeing parents forced to take legal action to protect services and clarify legal responsibilities
187. Ofsted and Care Quality Commission (CQC) joint inspections have also identified reductions in services such as short breaks. For example, Lancashire’s report⁵⁶ says “They struggle to identify any areas that have improved as a result of the implementation of the reforms. In fact, many described a reduction in services that were a strength in the past, such as access to short breaks”. This same report identifies weak arrangements for joint commissioning.

188. We are also concerned that young people between the ages of 18 and 25 who may move in and out of education, or leave education altogether, will not have access to a single EHC plan and may lose access to support; this would include many young people who need palliative care and, owing to the complexity of their conditions, do not continue in education.
189. In its written evidence, Acorns Children's Hospice Trust suggest there is great potential in joint posts and joint commissioning of service¹³. This provides a robust system for both families and for professionals trying to deliver the best care they can. They added that integrated working needs to become the norm and commissioners must take a strategic overview to ensure the best service is provided for children and families.
190. Other hospices highlighted the need for collaborative, integrated working. Alexander Devine Children's Hospice Service want to see statutory and voluntary service providers working more closely together³³.
191. We call on the government to make disabled children, including those with life-limiting conditions, a priority by providing ministerial leadership to ensure a cross-departmental approach to improving outcomes for disabled children and their families.
192. We call on the government to commission a review of health and social care law, to strengthen and clarify rights and entitlements for disabled children, including those with life-limiting conditions, and their families. As part of this, we ask the government to review whether the system of single assessments and plans should be extended to all disabled children and young people up to the age of 25 – not just those with a special educational need (SEN). Integrated personal budgets could be offered to all those with an integrated plan. A review should also consider how the law can make sure that local areas set out what disabled children, including those with life-limiting conditions, can expect from local services through a 'duty to provide' and how an England-wide framework for local offers could be created. Any system should ensure that children with life-limiting conditions and their families are clear which professional – or network of professionals – is coordinating their care and support.
193. Together for Short Lives has found that across England, NHS trusts mostly or usually make sure that children and young people with life-limiting conditions are cared for by a multi-disciplinary team¹¹.
194. The *NICE guideline on end of life care for infants, children and young people*¹ recommends that children's palliative care services should be based on managed clinical networks (MCNs), which coordinate and the planning and provision of providing care in local areas⁵⁷.
195. An MCN is "a linked group of health professionals and organisations from primary, secondary, and tertiary care, working in a coordinated way that is not constrained by existing organisational or professional boundaries to ensure equitable provision of high quality, clinically effective care . . . The emphasis . . . shifts from buildings and organisations towards services and patients⁵⁸."
196. MCNs help to build a strategic and joined-up approach to children's palliative care across health and social care services and bring together statutory and charitable providers.
197. East Anglia's Children's Hospices (EACH) assert that choices can only be exercised fully when there is an MCN, led by expert palliative care clinicians from multi-professional backgrounds, with formalised, funded and accountable systems and processes which support the child and family care journey from diagnosis (or birth) and into bereavement. Within the East of England children's palliative care MCN, EACH emphasise the necessity of an equipped and skilled workforce and adequate communication channels between service providers²⁸.
198. The MCN approach has already been adopted in Wales, where the All-Wales Managed Clinical Network works to support children and their families with life-limiting or life-threatening conditions by facilitating the delivery of appropriate specialist care in whatever clinical environment the child is located.
199. Together for Short Lives has found that across England, managed clinical networks or children's palliative care networks provide the full range of specialist paediatric palliative care interventions including use of alternative opioids¹¹.

200. We urge the government and NHS England to invest in supporting work to develop children's palliative care MCNs across the country.
201. NHS England, the Department of Health and Social Care and Health Education England should support children's palliative care networks to:
- develop solutions to common challenges
 - develop network improvement plans
 - build connections between high performing areas and those that have yet to implement local solutions – through buddying, mentoring and training
 - benchmark against each other and exchange local solutions through a central focus group or network of networks.

Strengthening accountability and transparency to drive improvements

In the end of life care choice commitment, the government says: “We will strengthen accountability and transparency to drive improvements. We will hold the NHS to account for improvements to end of life care through the Mandate to the NHS and we will hold HEE to account through its own Mandate. For the first time, we will develop a robust set of metrics that capture care quality, patient experience and personalisation in end of life care to track progress nationally on delivering high quality, personalised care. We will publish performance against key measures for every clinical commissioning group to drive up standards in every part of the country.”

202. We note that the NHS Outcomes Framework⁵⁹ includes the indicator “4.6 Bereaved Carers’ Views on the Quality of Care in the Last 3 Months of Life.” However, we understand that data is only collected from carers who are bereaved of adults and not children.
203. We call on the government to develop outcomes indicators which measure the extent to which children with life-limiting conditions can make choices about the palliative care they receive. They should reflect the outcomes set out in the NICE quality standard for end of life care for infants, children and young people⁴.



204. In its written evidence, NHS England states that work to deliver its end of life care programme is managed through a cross-system governance board, established October 2016. It says that the board brings together all partners and delivery plans in a cohesive and co-ordinated approach to gain greater impact for the limited resources available and assures the Department of Health and Social Care that the end of life care commitment will be achieved. Members of the board include NHS England directors, senior arm's length body (ALB) leads, the department, CCGs and representatives from the Ambitions Partnership who are all supporting work to deliver aims and objectives of the end of life programme⁴³.
205. We note, however, that the board does not include a representative of the children's palliative care sector.
206. We call on NHS England to make sure that a representative of the children's palliative care sector is added to the cross-system governance board that delivers its end of life care programme.
207. East of England Children and Young People Palliative Care Forum highlighted a lack of reliable national data on the incidence, prevalence and demographics for, meaning they are unable to provide a comprehensive choice of services for child and family²⁷.
208. We note that a new research study called "Make Every Child Count", funded by True Colours Trust and led by Dr Lorna Fraser, Director of the Martin House Research Centre at the University of York will give an up-to-date estimate of the number of babies, children and young people with life-limiting and life-threatening conditions across the UK⁶⁰. This should help to predict levels of need in the future.
209. When published, we call on the government and NHS England to take the results of the Make Every Child Count study into account. We ask them to help communicate its findings to commissioners and allocate funding to make sure that children's palliative care services can be planned, funded and provided to meet the need that the study identifies.
210. The Rainbow Trust, in their written evidence, state that the NICE guideline¹ has set out clearly 'what good looks like', especially in a clinical context. At the same time, work on a national bereavement pathway will provide valuable guidance on what good bereavement care and support entails, and the Ambitions framework offers a detailed view of what local action is required. Attention should therefore now be focused on how to turn each of these into a reality for all families at a time of resource and workforce constraints, and competing priorities within the health and social care system.



Acknowledgements

The APPG would like to thank the following individuals and organisations, without whom this inquiry would not have been possible:

- Our secretariat, Together for Short Lives
- Our group of expert advisers:
 - Anna Gill OBE (a parent of a young man with a life-limiting condition)
 - Nikki Lancaster (a parent bereaved of her son who died as a result of a life-limiting condition)
 - Sophie Dodgeon (Policy and Campaigns Manager, Rainbow Trust Children's Charity)
- All witnesses who travelled to Westminster to provide oral evidence (who are listed on pages 13-15), many of whom took annual leave and arranged for their shifts to be covered so that they could attend.
- All individuals and organisations who took the time to submit written evidence
- Jenny and Nicola, employees of BNP Paribas, who volunteered their time to help transcribe our oral evidence sessions
- Elizabeth Cooper.



Appendix one

What are life-limiting and life-threatening conditions? How do they affect children and young people?

Life-limiting conditions are those for which there is no reasonable hope of cure and from which people are expected to die. Life-threatening conditions or episodes are those for which curative treatment may be feasible but can fail. People with life-limiting conditions need continuing palliative care throughout the trajectory of their illness.

Life-limiting and life-threatening conditions in children and young people can be defined by the following four categories⁴⁷

1. Life-threatening conditions for which curative treatment may be feasible but can fail – such as cancer or congenital heart disease.
2. Conditions where premature death is inevitable but where there may be prolonged periods where the child is well – such as Duchenne muscular dystrophy.
3. Progressive conditions without curative treatment options, such as Batten disease.
4. Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death – such as severe brain injury.

Transition to adulthood for young people with life-limiting conditions

The needs of young people with life-limiting conditions and their families are complex. As a result, many find transition daunting. On leaving the comprehensive care offered by children's services, they will often have to deal with and establish important relationships with a range of unfamiliar agencies and professionals. The result can be gaps in services or fewer or less appropriate services⁶¹.

Like all young people, many of those with life-limiting conditions want to establish their independence; some want to be able to spend time away from older adults; some hope to go into further or higher

education and attain qualifications and skills; some wish to get a job, move into their own home, develop a social life and have relationships. Some young people also want to use their experiences to make things easier for other people in similar situations⁶¹. However, some young people will be cognitively impaired and will depend on their parents, carers or residential care until the end of their life.

For many young people with life-limiting conditions, transition into adult services often coincides with a rapid decline of their condition and eventual death. Young people should have plans in place where it is unclear whether their condition will stabilise, deteriorate or enter the end of life phase; this is known as 'parallel planning'.

Young people with life-limiting conditions require holistic support from a range of providers spanning health, social care, education, leisure and housing services. There is a general dearth of age and developmentally appropriate short break services for young people with life-limiting conditions in England. The Together for Short Lives Transition Taskforce has conceptualised the way that the five key agencies should work together as a 'pentagon of support' (see appendix two)⁶². This pentagon is underpinned by health and social care working closely together to provide a foundation for all the other provision, with work, leisure and education being the two 'enabling agencies' on either side and independent living as the 'capstone' at the top.

How many children and young people with life-limiting conditions are there?

*Fraser et al*⁶³ highlight the prevalence of life-limiting conditions in children and young people for every local authority district in England.

Overall, *Fraser et al* estimated that more than 40,000 children (0–19 years) in England in 2009/2010 were living with a life-limiting or life-threatening condition. The highest rate of increase between 2000 and 2010 was among those aged 16–19, who now account for 4,000, or one in ten, of 0–19-year-olds who need palliative care.

*Fraser et al*⁶⁴ estimate that there were 12,827 young adults aged 18 to 25 in England in 2009/10 who were living with a life-limiting or life-threatening condition. These numbers are also growing.

This is due to increasing life expectancy and improving quality of life resulting from advances in treatment and support. Children living with a life-limiting condition may survive to an age where they will need to transition to adult services.

CCGs and local authorities should be aware that not all children and young people with life-limiting conditions have a SEN. Children with conditions such as cancer or leukaemia may not have a SEN.

What do children and young people with life-limiting conditions need? What is children's palliative care?

Children and young people with life-limiting conditions need palliative care from the point at which their condition is diagnosed or recognised – often at birth – until the end of their lives. Families also need care and support throughout the trajectory of their child's illness, including after they have died. Palliative care for children and young people should⁶⁵:

- meet their physical, emotional, social and spiritual needs
- aim to enhance their quality of life and support their family in coming to terms with their condition and the care they will need
- help families understand how the young person's condition and their needs may change over time

- include managing distressing symptoms, providing short breaks and care through death and bereavement
- be provided in ways which are appropriate to their age and stage of development; this means care provided in age and developmentally appropriate settings by professionals who are skilled in working with them.

Children's palliative care is different to palliative care for adults. Whereas the majority of adults only need palliative care at the end of their lives, children with life-limiting and life-threatening conditions require palliative care over a much longer period, often from birth as they live with the instability of their condition. It is common for their conditions to fluctuate and, as such, it is often much more difficult to identify when a child is moving into their end of life phase. Children with life-threatening and life-limiting conditions often have complex disabilities, while the range of health conditions which results in children requiring children's palliative care is more diverse. Children's palliative care is an approach to care in conjunction with curative treatments.

Palliative care does not begin at the end of life but is involved from the time a child is diagnosed with a life-limiting illness.

A comprehensive local children's palliative care service spans health, social care and education. Therefore joint commissioning is vital. It is a whole-family approach and has the following characteristics:



- It is flexible and focused on children, their parents, their carers and their siblings
- It is accessible 24 hours a day, seven days a week, 365 days a year – from diagnosis or recognition that a condition will shorten a child's life, to bereavement
- It supports and enables children and families to choose the type, location and the provider of the care they receive and allows them to change their mind
- It is not age, time or diagnosis specific – 15% of children who need children's palliative care have no definitive underlying diagnosis⁶⁶
- It is multi-disciplinary and multi-agency
- It is accessible to people of different faiths, culture, ethnicity and locations
- It includes pre and post-bereavement support for families
- It is able to manage symptoms
- It supports parents in caring for their children according to their needs and wishes
- It supports and enables smooth transitions for young people with life-limiting and life-threatening conditions who move from children's to adults' services.

Palliative care should be provided in ways which are appropriate to a child or young person's age and development; this means care provided in age and developmentally appropriate settings by professionals who are skilled in working with them.

Who provides services to children and young people with life-limiting conditions?

Universal, targeted and specialist children's palliative care is delivered by a web of providers; a significant proportion of children's palliative care is delivered by the voluntary sector. Sustained and effective children's palliative care should be provided in all local areas. There should be no gap as young people move from children's to adult services. At all times, locally available and community-led children's palliative care should be at the heart of provision to children. This should be supported by:

- Specialist medical input (for example, medical consultants with expertise in the child's condition)
- Community children's nursing teams
- Children's hospice services
- Specialised children's palliative care providers
- Access to secondary and tertiary care
- Emotional and psychological support
- Local authority children's services – practical care and support, including services providing equipment to disabled children, education, housing and leisure
- Community paediatricians
- Primary care.

Together for Short Lives' online directory of services⁶⁷ sets out which organisations are providing children's palliative care in their local area. Our directory includes maps, lists and a search function. The local offer may also be helpful.

Appendix two

Northern Ireland

There are 1,300 children in Northern Ireland with life-limiting or life-threatening conditions. In 2016, the Department of Health in Northern Ireland published *'Providing High Quality Palliative Care for Our Children: A Strategy for Children's Palliative and end-of-life care 2016-26'*⁶⁸.

The strategy was produced by a project group of healthcare professionals, officials and representatives of the Northern Ireland Children's Hospice. It recommends a series of actions to enhance the existing care and support available for children and young people with life-limiting or life-threatening conditions and their families. To achieve this, the strategy contains 23 clear objectives that must be realised to transform children's palliative care in Northern Ireland. A 'New Care Model' set out in the strategy identifies that the child, their family and carer must be at the centre of their care and that their care plan should be based on a holistic assessment of the child's needs.

Scotland

There are 15,000 babies, children and young people in Scotland with life-limiting and life-threatening conditions⁶⁹, a number which is growing as a result of advances in medical technology and better care.

Scottish Government's 'Strategic Framework for Action for Palliative and End of Life Care'⁷⁰ states that after their child had died, families should be able to say:

- their child received health and social care that supported their wellbeing, irrespective of their diagnosis, age, socio-economic background, care setting or proximity to death
- they and their child had opportunities to discuss and plan for a future possible decline in health, preferably before a crisis occurred, and were supported to retain their independence for as long as possible
- people knew how to help and support each other at times of increased health need and in bereavement, recognising the importance of families and communities working alongside formal services
- the staff who care for them were empowered to exercise their skills and provide high quality person-centred care.

In the Scottish Government's 'Strategic Framework for Action for Palliative and End of Life Care, it commits to working with stakeholders to:

- support Healthcare Improvement Scotland in providing Health and Social Care Partnerships with expertise on testing and implementing improvements in the identification and care co-ordination of those who can benefit from palliative and end of life care
- provide strategic commissioning guidance on palliative and end of life care to Health and Social Care Partnerships
- support the development of a new palliative and end of life care educational framework
- support and promote the further development of holistic palliative care for the 0-25 years age group
- support the establishment of the Scottish Research Forum for Palliative and End of Life Care
- support greater public and personal discussion of bereavement, death, dying and care at the end of life, partly through commissioning work to facilitate this
- seek to ensure that future requirements of e-Health systems support the effective sharing of individual end of life/Anticipatory Care Planning conversations
- support clinical and health economic evaluations of palliative and end of life care models
- support improvements in the collection, analysis, interpretation and dissemination of data and evidence relating to needs, provision, activity, indicators and outcomes in respect of palliative and end of life care
- establish a new National Implementation Support Group to support the implementation of improvement actions.

In 2016 the Scottish Government committed approximately £30 million of statutory funding to children's palliative care over the next five years. This followed the publication, in 2015, of research funded by the Scottish Government and commissioned by Children's Hospices Across

Scotland (CHAS) which identified the number of babies, children and young people with life shortening conditions in Scotland. This research showed that the 15,000 babies, children and young people in Scotland with palliative care needs was a much higher number than previously thought⁶⁹. The study also showed that two thirds of babies, children and young people who die each year in Scotland do so without access to specialist palliative support.

The increased statutory funding will help CHAS to reach its goal of reaching every family in Scotland who needs its care, as set out in the CHAS Plan. CHAS will continue to work in partnership with the Scottish Government, health and social care colleagues and other key stakeholders across Scotland to support and promote the further development of holistic palliative care for the 0-25 years age group.

Wales

There are 1,000 babies, children and young people in Wales with life-limiting and life-threatening conditions⁶³, a number which is growing as a result of advances in medical technology and better care. In 2011, there were 222 registered child deaths in Wales⁷¹. A significant proportion were seriously ill children who need end of life care.

The Welsh Government's 'Palliative and End of Life Care Delivery Plan – March 2017'⁷² states that, after their child had died, families would be able to say:

- Conversations about their child's serious illnesses were appropriate and empowered them and their child to take informed decision
- Their child's illness and the fact that they needed palliative care – were identified early
- They and their child experienced care that met their needs and preferences
- They and their child felt supported at all stages and by all staff
- They and their child had the information they needed to make decisions
- Professionals caring for them and their child were equipped in all health care settings to support them.

NICE calculate that if the Welsh Government invested £690,000 in implementing its guideline on end of life care for children¹, non-cash savings worth £1.9million would be released back into the NHS in Wales.

In the 'Palliative and End of Life Care Delivery Plan – March 2017'⁷², the Welsh Government states that to plan effectively for their populations, local health boards must build and lead coalitions with NHS Trusts, locality networks, GPs, nursing homes, pharmacists, dentists, opticians, social services, prison services and the third sector voluntary bodies. An all-Wales Paediatric Palliative Care Network and Implementation Group, chaired by Dr Richard Hain, enables a one Wales approach, providing peer support and acting as an effective information sharing platform.

In 2018, a Cross Party Group for Hospices and Palliative Care⁷³ inquiry found a number of similar challenges facing children and families in Wales as we have found in our inquiry in England. Among a number of recommendations relating to children's palliative care, it recommended that:

- local health boards should demonstrate how they consider end of life care needs in determining their out-of-hours coverage and work cooperatively to resource children's out-of hours services at an all-Wales level
- as part of wider reviews of out-of-hours care, end of life care needs should form a significant element in determining the level of coverage required within local health board areas, including contributing resource to provide all-Wales coverage. The group stated that this should include working cooperatively with the End of Life Care Implementation Board and children's hospices to secure sustainable out-of-hours coverage for children's palliative care by ensuring that appropriate consultant cover is available
- the End of Life Care Implementation Board should develop a robust action plan to address shortages in community nursing for children and young people who need palliative care
- children and young people with life-limiting conditions should have the same choices about preferred place of care and/or death as adults at the end of life. For this to happen, the variation in numbers and skills of community children's nurses must be addressed to enable the delivery of end of life care for children in their own homes
- the End of Life Care Implementation Board should work with local health boards and children's hospices to identify gaps in extant provision and work together to enhance the skills needed to support current community teams to develop community children's nurses with appropriate qualifications in children's palliative care. This should involve creating specialist posts to support the development of the existing workforce, where necessary.

Appendix three

The officers of our APPG are as follows:

Co-chairs

- Dr Caroline Johnson MP (Conservative, Sleaford and North Hykeham)
- Catherine McKinnell MP (Labour, Newcastle upon Tyne North)

Vice-Chairs

- Sarah Champion MP (Labour, Rotherham)
- Neil Gray MP (SNP, Airdrie and Shotts)
- Jim Shannon MP (DUP, Strangford).

Members

- Dr Lisa Cameron MP (SNP, East Kilbride, Strathaven and Lesmahagow)
- The Lord Carlile of Berriew (not affiliated to a political party)
- Martyn Day MP (SNP, Linlithgow and East Falkirk)
- Mary Glindon MP (Labour, North Tyneside)
- Luke Graham MP (Conservative, Ochil and South Perthshire)
- Carolyn Harris MP (Labour, Swansea East)
- Sharon Hodgson MP (Labour, Washington and Sunderland West)
- Darren Jones MP (Labour, Bristol North West)
- The Earl of Listowel (Crossbench)
- David Linden MP (SNP, Glasgow East)
- Paul Masterton MP (Conservative, East Renfrewshire)
- Steve McCabe MP (Labour, Birmingham Selly Oak)
- Jessica Morden MP (Labour, Newport East)
- Alison McGovern MP (Labour, Wirral South)

- Sheryll Murray MP (Conservative, South East Cornwall)
- Liz McInnes MP (Labour, Heywood and Middleton)
- Rt Hon Stephen Timms MP (Labour, East Ham).

Secretariat services to the APPG are provided by Together for Short Lives. Please direct any enquiries about our APPG, inquiry or report to:

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Appendix four

The following individuals and organisations submitted written evidence to our inquiry:

- [Acorns Children's Hospice Trust](#)
- [Alexander Devine](#)
- [Caroline Blurton](#)
- [Children's Hospices Across Scotland](#)
- [Chiltern Music Therapy](#)
- [CLIC Sargent](#)
- [Coventry & Warwickshire Children and Young People's Palliative Care](#)
- [Department of Health](#)
- [East Anglia Children's Hospices](#)
- [East of England Children and Young People Palliative Care Forum](#)
- [Dr Alison Guadagno](#)
- [Dr Fauzia Paize](#)
- [Francis Edwards](#)
- [NHS England](#)
- [Rainbow Trust Children's Charity](#)
- [Royal College of Nursing \(RCN\)](#)
- [Royal College of Paediatrics and Child Health \(RCPCH\)](#)
- [Steph Nimmo](#)
- [Stoke and Staffordshire Children's Palliative Care Network](#)
- [Sue Croucher](#)
- [The Amber Trust](#)
- [Yvonne Julien](#)

The following individuals provided oral evidence to our inquiry:

Session one: 7 February 2018

- Lucy Watts MBE, a young woman who has a life-limiting condition
- Junior Jimoh, a young man who has a life-limiting condition
- Doug Morris, a father of a young man who has a life-limiting condition
- Stephanie Nimmo, a bereaved parent of a child who died as a result of a life-limiting condition
- Carly and Paul Hadman, bereaved parents of a child who died as a result of a life-limiting condition

Session two: 21 February

- Dr Sat Jassal (Medical Director, Rainbows Hospice for Children and Young People)
- Francis Edwards (Palliative Care Liaison Nurse, University Hospitals Bristol NHS Foundation Trust)
- Julie Potts (Diana Service Palliative Care Lead Nurse, Leicestershire Partnership NHS Trust)
- Dr Fauzia Paize (Consultant Neonatologist, Liverpool Women's NHS Foundation Trust).
- Dr Linda Maynard (Consultant Nurse Children's Palliative Care, East Anglia's Children's Hospices).
- Maria McGill (Chief Executive, Children's Hospices Across Scotland (CHAS)).
- Toby Porter (Chief Executive Acorns Children's Hospice).

Session three: 7 March

- Dr Renee McCulloch (Chair, College Specialty Advisory Committee – Paediatric Palliative Medicine (PPM), Royal College of Paediatrics and Child Health). Dr McCulloch is also a Consultant in PPM and Guardian of Safe Working at The Louis Dundas Centre, Great Ormond Street Hospital for Children NHS Foundation Trust.

- Dr Simon Clark (Officer for Workforce Planning, Royal College of Paediatrics and Child Health).
- Dr Emily Harrop (Chair, NICE Clinical Guideline Development Group). Dr Harrop is also Consultant in Paediatric Palliative Care at Helen and Douglas House Hospices.

Session four: 14 March

- Lindsey Barron, Integrated Children's Commissioner, Luton Council and Luton Clinical Commissioning Group.
- Julie Bayliss, Consultant Nurse Paediatric Palliative Care, Great Ormond Street Hospital Foundation Trust.
- Professor Bernie Carter, Professor of Children's Nursing, Edge Hill University.
- Rachel Cooke, Bereavement Service Manager and Joint Manager, Child Death Helpline, Great Ormond Street Hospital Foundation Trust (representing the Royal College of Nursing).
- Dr Helena Dunbar, Senior Lecturer, School of Nursing and Midwifery, De Montfort University.
- Dr Sue Neilson, School of Nursing, University of Birmingham.

Recordings of all of the oral evidence sessions are available to download and listen to online at <https://togetherforshortlives.podbean.com>.

Transcriptions of all of the oral evidence sessions are available to download from www.togetherforshortlives.org.uk/appg.

Appendix five

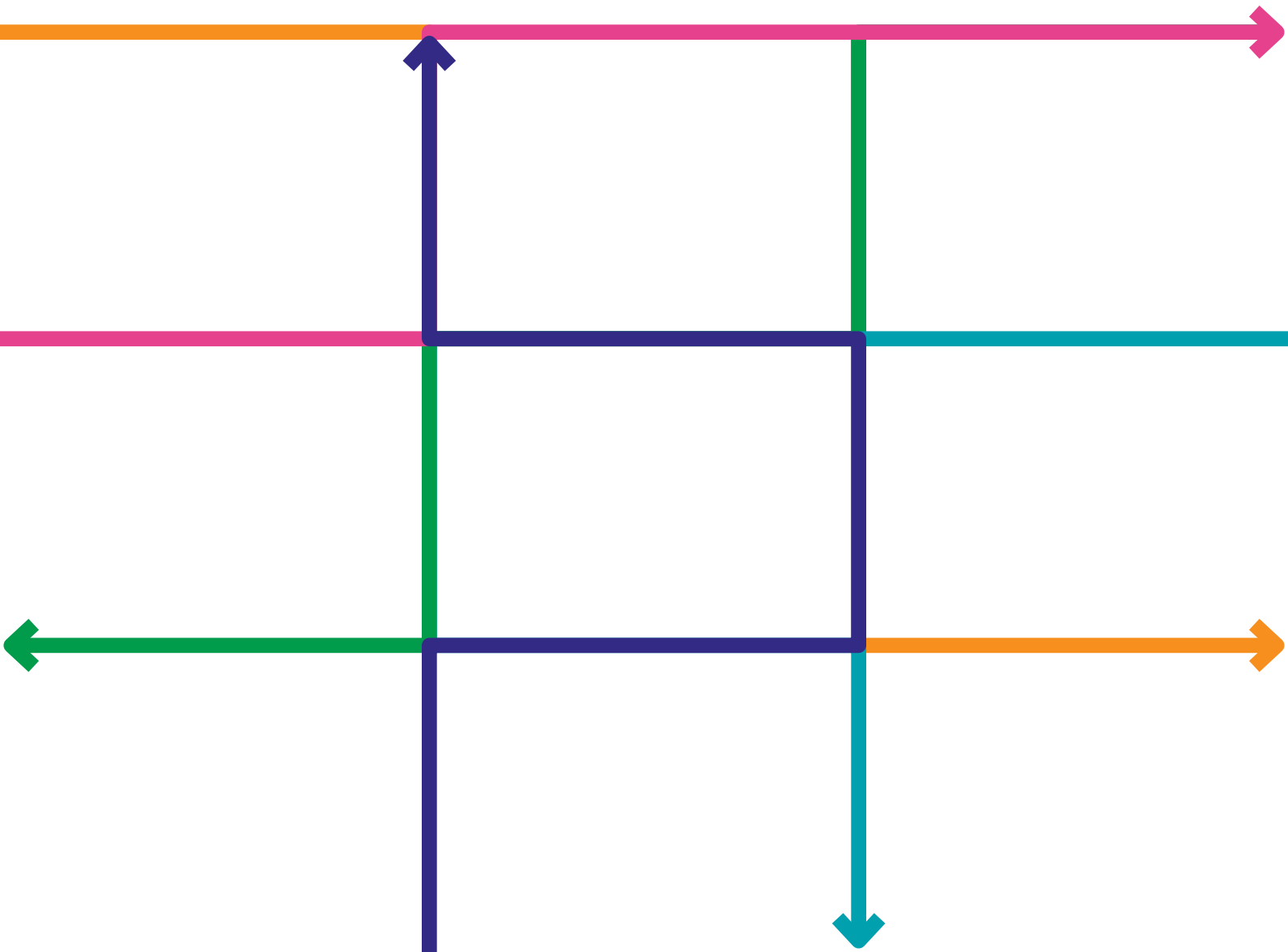
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20. Level 3: a paediatrician (consultant or Staff or Associate Specialist (SAS) doctor) who has developed a special interest in paediatric palliative medicine, an established children's hospice doctor or GP with Special Interest (GPWSI) in paediatric palliative care. Likely to have a relevant postgraduate qualification such as the Cardiff Diploma in Palliative Medicine (paediatrics) (APPM/RCPCH,2015).
21. Level 4: a consultant paediatrician in paediatric palliative medicine, or a small number of children's hospice medical leaders (mainly leaders in sub-specialty formation and development, and with roles beyond their local hospice), and who have a substantive role in children's palliative medicine. Manage uncommon symptoms; understand principles in order to develop a logical approach even where there is no evidence basis. Considerable emphasis on leading and developing services within and beyond the local hospice, and on supporting and teaching other professionals involved with children with life-limiting conditions who are not trained in palliative medicine (APPM/RCPCH, 2015).
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ISBN: 1 898 447 40 3