Developing the long-term plan for the NHS: a consultation response from Together for Short Lives

September 2018

About us

- We are the UK charity for children's palliative care. We are here to support and empower families caring for seriously ill children, and to build a strong and sustainable children's palliative care sector – so that no family is left behind.

- We directly support children and families through our helpline and the information and resources on our website, which help ensure that families can find the right local services and make the right choices about their child's care.

- We support all the professionals and children's palliative care services that deliver lifeline care. We have over 1,000 members, including children hospices, voluntary sector organisations and statutory service providers. By working together, we provide a strong and unified voice for the sector, and help services deliver the best quality care and support tailored to each family's needs. We are responding to this consultation on behalf of our members.

Introduction

- We welcome the fact that NHS England intends to develop a long-term plan for the NHS. We also welcome this opportunity to help shape it.

- We are keen to make sure that the NHS is able to meet the needs and wishes of the 40,000 babies, children and young people in England with life-limiting and life-threatening conditions and their families[1]. They include some of the most vulnerable children in our society and those with the most complex health needs.

- There are a wide range of services from health, social care and education involved in the provision of children's palliative care which need to work together to provide more seamless care. One effective way to achieve more integrated working is through networks, which have the potential to bring together different organisations to share best practice and provide a structure through which providers and commissioners can strategically plan for service development and plan services effectively. They also offer potential for feeding in the voices of service users. These informal children's palliative care networks are currently established in almost all regions and countries of the UK and are to varying degrees achieving this potential. There are also some networks operating at a more local level allowing for local operational planning and commissioning at point of delivery as opposed to more region-wide strategic planning.

- Currently, there is too much unjustified variation in the way in which the children's palliative care they rely on is planned, funded and provided by the NHS and its partners. This is despite a clear policy framework which sets out the care and support they should expect in the government's end of life care choice commitment[2], NICE guidance[3, 4] and the Ambitions for Palliative and End of Life Care[5].

---

1 Fraser LK, Parslow RC, McKinney PA, Miller M, Aldridge JM, Hain R, Norman P. 2012. Life-limiting and life-threatening conditions in children and young people in the United Kingdom; final report for Together for Short Lives. Available to download from: http://bit.ly/1z24ZQw

2 Department of Health. 2016. 'Our Commitment to you for end of life care: The Government Response to the Review of Choice'. Available to download from: http://bit.ly/2oOUsfj

- Time is short for children with life-limiting conditions and their families and many will not benefit from the new NHS plan if it only delivers reform in the long-term. It is crucial that the new NHS plan helps them to achieve the outcomes that they want from their lives as soon as possible.

- It is important to convey that palliative care for babies, children and young people spans two of the life-stages identified by NHS England (care for children and young people and care for people approaching the end of their lives). In its long-term plan, it is vital that NHS England acknowledges that some children do not reach adulthood as a result of life-limiting or life-threatening conditions. We call on NHS England to use the plan to set out how it will meet the government's end of life care choice commitment for babies, children and young people.

- Together for Short Lives fully supports the goal for children and young people's health which we have provided input to and which has been prepared for NHS England by:

    - CLIC Sargent
    - National Children's Bureau
    - Office of the Children's Commissioner
    - Royal College of Paediatrics and Child Health
    - The Children's Society.

- We also support the submission made by the Health and Wellbeing Alliance.

- In this response, we have answered the consultation questions which are most relevant to children with life-limiting conditions, their families and the professionals and services who provide them with palliative care.

Our submission

1. Life stage programmes

1.2 How can we improve how we tackle conditions that affect children and young people?

and

1.4 How can we ensure children living with complex needs aren't disadvantaged or excluded?

Together for Short Lives welcomes the fact that children and young people have been recognised as an important life-stage for the new NHS plan to include. However, we share the concern that health outcomes for children and young people in England are worse than in similar countries and that their experience of care is sometimes poor. This is simply not good enough. Whilst there have been improvements, they have not led to comprehensive or system wide changes that are really required to improve outcomes.

---

3 The National Institute for Health and Care Excellence. 2016. End of life care for infants, children and young people with life-limiting conditions: planning and management - NICE guideline [NG61]. Available to download from: http://bit.ly/2ODg2hY

[4] The National Institute for Health and Care Excellence. 2017. End of life care for infants, children and young people – NICE quality standard [QS160]. Available to download from: http://bit.ly/2M6BHx3

5 Ambitions for Palliative and End of Life Care. 2015. Available to download from: http://endoflifecareambitions.org.uk/

The NHS must play a positive role in the lives of children and young people - and take system-level responsibility for their outcomes. Improving health outcomes for children is morally and economically the right thing to do.

Together for Short Lives joins CLIC Sargent, the National Children's Bureau, the Office of the Children's Commissioner, the Royal College of Paediatrics and Child Health and the Children's Society in proposing a new goal that "by 2028, children and young people will have better physical health, mental health and wellbeing. Health inequalities will be halved and mortality rates will be amongst the lowest in Western Europe. Children and young people, and their parents and carers, will experience a seamless service delivered by an integrated health and care system. There will be a skilled workforce that listens to them, responds, and meets their needs".

It is crucial that, as a result of the new plan, babies, children and young people with long-term conditions, disabilities and complex needs will be supported to live more healthily and to have better control over the care they receive. For adults, long-term conditions are now seen as a central task of the NHS; there is a recognition that caring for these needs requires a partnership with patients over the longer term rather than providing single, unconnected "episodes" of care. We believe the same is right for children and young people.

The government's commitment to the 40,000 babies, children and young people in England with life-limiting and life-threatening conditions[6] is clear and welcome. Together for Short Lives supports 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. There are 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) states[7] 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[8]:

    - 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.

---

[6] Department of Health. 2016. 'Our Commitment to you for end of life care: The Government Response to the Review of Choice'. Available to download from: http://bit.ly/2oOUsfj

[7] The National Institute for Health and Care Excellence. 2016. End of life care for infants, children and young people with life-limiting conditions: planning and management - NICE guideline [NG61]. Available to download from: http://bit.ly/2ODg2hY

[8] Together for Short Lives. 2017. A national overview of the readiness of the children's palliative care sector to implement the NICE End of Life Care for Infants, Children and Young People: Planning and Management Guideline. Available to download from: http://bit.ly/2Kdzfnw

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. We have found that 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[9].

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 guidance[10]. However, too many parents are unable to access short breaks when they need 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[11]:

   - 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[12]. 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%)

---

[9] Together for Short Lives. 2017. Commissioning children's palliative care in England: 2017 edition. http://bit.ly/2MbiE4O

10 The National Institute for Health and Care Excellence. 2016. End of life care for infants, children and young people with life-limiting conditions: planning and management - NICE guideline [NG61]. Available to download from: http://bit.ly/2ODg2hY

[11] Together for Short Lives. 2017. Commissioning children's palliative care in England: 2017 edition. http://bit.ly/2MbiE4O

[12] Fraser LFK, Miller M, Aldridge J, PA, Parslow RC. 2013. Prevalence of life-limiting and life-threatening conditions in young adults in England 2000-2010; final report for Together for Short Lives. Available to download from: http://bit.ly/1z24VQQ

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)[13] 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 symptoms[14]. However, NHS England states[15] that specialist children's palliative care teams should be led by medical consultants working at Paediatric Palliative Care Competency Level 4[14]. 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.

    Across England, specialist children's palliative care teams are only sometimes led by Level 4 consultants[16].

5. **Access to advance care planning:** NICE states[7] 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[17].

There are four barriers which explain why the government's choice commitment is at serious risk of not being met and where there are opportunities NHS England to work with partners to overcome:

1. **Leadership and accountability:** the way in which NHS CCGs and local authorities commission children's palliative care in hospitals, children's hospices and the community represent a postcode lottery[18]. Almost half (46%) of CCGs are failing to implement the

---

[13] The National Institute for Health and Care Excellence. 2016. End of life care for infants, children and young people with life-limiting conditions: planning and management - NICE guideline [NG61]. Available to download from: http://bit.ly/2ODg2hY

[14] Association for Paediatric Palliative Medicine Education Subgroup And Paediatric Palliative Medicine College Specialty Advisory Committee, Royal College of Paediatrics and Child Health. 2015. Curriculum in Paediatric Palliative Medicine. Available to download from: http://bit.ly/2AvDzOJ

[15] NHS England. 2013. E03/S/h – 2013/14 NHS standard contract for paediatric medicine: palliative care particulars, schedule 2 – the services, A – service specifications. Available to download from: bit.ly/11yjtVS

[16] Together for Short Lives. 2017. A national overview of the readiness of the children's palliative care sector to implement the NICE End of Life Care for Infants, Children and Young People: Planning and Management Guideline. Available to download from: http://bit.ly/2Kdzfnw

[17] Together for Short Lives. 2017. A national overview of the readiness of the children's palliative care sector to implement the NICE End of Life Care for Infants, Children and Young People: Planning and Management Guideline. Available to download from: http://bit.ly/2Kdzfnw

[18] Together for Short Lives. 2017. Commissioning children's palliative care in England: 2017 edition. http://bit.ly/2MbiE4O

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 long-term plan to specify that the end of life care choice commitment be implemented in full for babies, children and young people. We also call on NHS England to 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.**

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 welcome and support NHS England's intention to develop a model to help STPs and ICSs to commission children's palliative care, underpinned by a new service specification.**

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[19]:

    - 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 due to additional demand

    - on average, the overall amount of statutory funding for charities providing children's palliative care was 22% in 2016/17. This is the same as that recorded in 2015/16 and lower 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 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%

    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.

    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 care[7], non-cash savings worth

---

[19] Together for Short Lives. 2016. On the brink: a crisis in children's palliative care funding in England. The results of Together for Short Lives and Hospice UK's survey on children's palliative care funding and commissioning in England 2015/16. Available to download from: http://bit.ly/2f7HowK

£34.7million would be released back into the NHS in England[20]. **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 also call for 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.**

4. **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 NHS England'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) 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 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 also urge NHS England to invest in supporting work to develop of children's palliative care MCNs across the country.**

1.3 How should the NHS and other bodies build on existing measures to tackle the rising issues of childhood obesity and young people's mental health?

We agree with the proposals in the government's Transforming Children and Young People's Mental Health Provision Green Paper[21] which state that all schools and colleges will be incentivised and supported to identify and train a Designated Senior Lead for Mental Health who will oversee the approach to mental health and wellbeing. We also agree that Mental Health Support Teams should be set up to locally address the needs of children and young people with mild to moderate mental health issues, working with schools and colleges to link with more specialist NHS services.

In particular, we welcome the focus that the teams will have on supporting young people who have been bereaved. We welcome the fact that this support would not be limited to those children in mainstream education - and could be available more widely. We call for the work of these teams not to be restricted to schools, colleges and NHS services: we ask that they also work with voluntary sector children's palliative care providers, such as children's hospices, which care for children and young people who have been bereaved of siblings. This would make sure that these children are identified and offered the support they need.

1.5 What is the top prevention activity that should be prioritised for further support over the next five and ten years?

---

20 NICE. 2016. End of life care for infants, children and young people with life-limiting conditions: planning and management 'Resource Template'. Available at: http://bit.ly/2k4V2jZ. This figure for the whole of England was calculated using the 'Population & resource summary' tab.

[21] Department of Health and Social Care and Department for Education. 2017. Transforming children and young people's mental health provision: a green paper. Available to download from: https://www.gov.uk/government/consultations/transforming-children-and-young-peoples-mental-health-provision-a-green-paper

Investing in children's palliative care. 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.[20] This savings could be achieved by commissioning a range of palliative care services which make sure that children and families can choose how and where they receive care and support – including at home or in a children's hospice. This would in turn reduce their demand for expensive, unplanned, emergency care, particularly out of hours and at weekends.

1.7 What should be the top priority for addressing inequalities in health over the next five and ten years?

Commissioning and providing palliative care services for babies, children and young people in a way which is consistent with the government's end of life care choice commitment, NICE guidance and the Ambitions for Palliative and End of Life Care[22].

1.10 What is the best way to measure, monitor and track progress of prevention and personalisation activities?

and

1.15 How can we ensure that people, along with their carers are offered the opportunity to have conversations about their priorities and wishes about their care as they approach the end of their lives?

The National Institute for Health and Care Excellence (NICE) 'End of life care for infants, children and young people with life-limiting conditions: planning and management' clinical guidance that was published in December 2016 sets out the range of services that children and young people should be able to access. Commissioners are expected to meet all the requirements of new NICE guidance, though this is not mandated by NHS England. The quality standard[23] on the same topic comprises six quality statements that children and families should be entitled to:

- Children with life-limiting conditions and their parents or carers should be involved in developing an ACP.
- Children should have a named medical specialist who leads and coordinates their care.
- Children and their parents or carers should be given information about emotional and psychological support, including how to access it.
- Children should be cared for by a multidisciplinary team that includes members of a specialist children's palliative care team.

---

[22] Ambitions for Palliative and End of Life Care. 2015. Available to download from: http://endoflifecareambitions.org.uk/

[23] The National Institute for Health and Care Excellence. 2017. End of life care for infants, children and young people – NICE quality standard [QS160]. Available to download from: http://bit.ly/2M6BHx3

- Parents or carers of children approaching the end of life should be offered support for grief and loss, including after their child has died.

- Children approaching the end of life and being cared for at home should have 24-hour access to both children's nursing care and advice from a consultant in children's palliative care.

We call on NHS England to hold commissioners to account for the way in which they deliver these outcomes for children with life-limiting conditions and their families.

2. Clinical priorities

Cancer

Cancer is a life-threatening condition for which curative treatment can fail. Despite improving survival rates, cancer is the leading cause of death in children, teenagers and young adults. Children and young people with cancer may need palliative care if their treatment fails. They may also need it alongside curative treatment, and/or if they experience a temporary, acute crisis, irrespective of how long the threat to their life lasts.

At whatever point a poor prognosis is recognised for a child or young person with cancer, it is crucial that the family is made aware. This should be the first milestone in the child or young person's palliative care pathway. Children's palliative care referral pathways should be commissioned and implemented to make sure that children and young people with cancer are referred to these services as soon as possible.

All children and young people with cancer should be offered an ACP which includes planning with their families for the end of their life. They should be supported to collaborate with their care providers to develop these plans. This should be done at a pace which suits the family and in a way which reflects their understanding of the situation.

Children and young people with cancer, and who need palliative care, require support from a range of professionals and organisations from health, social care and other agencies. Every family of a child with cancer should receive a child and family centred multi-disciplinary and multi-agency assessment of their needs as soon as possible after their child is recognised as likely to die prematurely. As a result of this assessment, every child and family should have a multi-disciplinary multi-agency care plan, developed in partnership with them.

Children and young people with cancer should be supported to have conversations about dying.

Children and young people with cancer and their families should be offered the choice of how and where they receive palliative care, including at the end of their lives. Professionals should support children and families to make these choices.

Where a child who has had cancer has died, or is expected to die, bereavement support should be available for the child and family.

Young people with cancer should experience smooth transitions from children's to adults' services - and receive palliative care which is appropriate to their age.

There are barriers to research into children's palliative care. The Cancer Strategy recommended that, by September 2016, a proposal should be developed to ensure that all children, teenagers and young adults diagnosed with cancer are asked at diagnosis for consent for their data and a tissue sample to be collected for use in future research studies. The strategy also states that NHS England should work with research funders to make best use of these resources in the future. We ask that the joint submission emphasises the need for this proposal and joint work with funders to be realised.

Kinder treatments are needed for children and young people with cancer to reduce the risk of those who survive having to live with long-term conditions resulting from the treatments they are given. Children and young people who survive cancer may need palliative care later in life.

Mental health

The pressure on parents of having a child with a life-limiting condition is immense. Most relationships will suffer, with 36% experiencing a breakdown of the family[24].

Many mothers and fathers will need to give up work and this, combined with the extra costs of caring for a seriously ill child, means that many families may live in poverty.

Many brothers and sisters will miss school or experience educational difficulties, and many will be bullied or feel isolated at school.

Children with life-limiting conditions - and their families - rely on frequent short breaks for respite to enable them to relieve this stress, spend time as a family and do the things that other families do. Every family's needs are different: some need overnight, residential short breaks either with or without their child; some need short breaks for only a few hours at a time, provided at home or in hospital. Some will need a mix of both.

Overnight short breaks for children and young people with life-limiting conditions usually include some element of clinical care to meet their often complex health needs, even if it is just an initial clinical assessment. Therefore, NHS organisations have a specific role in jointly planning and funding these services with local authorities.

Too many clinical commissioning groups (CCGs) and local authorities in England are failing to support short breaks[25]. 84% of CCGs reported that they commission short breaks for children who need palliative care, which is an increase from our 2016 research, when just 77% commissioned these services. However, more than one in five (21%) local authorities do not commission short breaks for children with life-limiting and life-threatening conditions, despite having a legal duty to do so. This figure has declined since 2016, when one in seven (14%) reported that they do not provide these short breaks.

New UK-wide research conducted by Julia's House Children's Hospice and Bournemouth University[26] has examined the impact that caring for a child with a life-limiting or life-threatening condition has had on parental relationships. 17 children's hospices from across England and Scotland took part. The research has found that:

- 64% of divorced or separated parents cited having a child with complex needs as a reason for the breakdown of their relationship
- of those couples, 75% had no access to short breaks at that time
- most parents (74%) rated short breaks provided by children's hospices as having a direct, positive effect on their relationship with a partner, giving them rare time together as a couple. Others used short breaks to spend time with their other children or just enjoyed time to themselves, regaining some balance in their lives, ultimately benefitting the whole family

---

24 Steele R. 2000. Trajectory of certain death at an unknown time: children with neurodegenerative LTC illnesses. Cancer Journal of Nursing Research 32, 49-67.
25 Together for Short Lives. 2017. Commissioning in England 2017. Available to download from: www.togetherforshortlives.org.uk/commissioning2017
[26] Mitchell, A., 2017. 'Can we fix it?!': understanding the impact of children's hospice short breaks on parental relationships of life-limited and life-threatened children and young people. PhD Thesis. Bournemouth University, Faculty of Health and Social Sciences.

- couples whose relationships were identified as ‘non-distressed’ by the research were found to have received on average 43% more hours of short breaks from a children’s hospice compared to those who were in distressed relationships.

We ask NHS England to work with us, the Department of Health and Social Care and the Department for Education to issue guidance to NHS clinical commissioning groups (CCGs), sustainability and transformation partnerships (STPs) and local authorities. This should remind them that they are all responsible for planning and funding short breaks for these children in their local areas.

3. Enablers of improvement

3.1 What is the size and shape of the workforce that we need over the next ten years to help deliver the improvements in services that we would like to see?

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.

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.

From a survey of children's hospice organisations in the UK which Together for Short Lives undertook in 2016[27], we found 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.

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 service[28]. The Office of National Statistics estimates that there are 13,770,873 children aged 0-18 in England[29]. 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 2018[30].

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

---

[27] Together for Short Lives. 2017. The state of the UK children's hospice nursing workforce: a report on the demand and supply of nurses to children's hospices. Available to download from: http://bit.ly/2kcoyqb

[28] RCN. 2014. The future for community children's nursing: challenges and opportunities. P.10. Available to download from: http://bit.ly/1QgLhZb.

[29] Office for National Statistics. 2018. Population Estimates Analysis Tool. Available to download from: http://bit.ly/2KhPnE5

[30] NHS Digital. 2018. NHS Workforce Statistics – March 2018, Provisional statistics: Staff Group, Area and Level. Available to download from: http://bit.ly/2LNDH0D

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.

3.2 How should we support staff to deliver the changes and ensure the NHS can attract and retain the staff we need?

We call on NHS England to work with 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. They should 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.

Health Education England and the Council of Deans of Health should 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.

The Council of Deans of Health should encourage university undergraduate nurse programmes to adopt the new Nursing and Midwifery Council (NMC) standards for nurses[31], including those elements which relate to providing children's palliative care.

3.5 How could services like general practice and pharmacy, work with other services like hospital services to better identify and meet the urgent and long-term needs of patients?

GPs can play a really important role in children's palliative care. They are well placed to inform families about palliative care provision locally, ensure continuity of care and work collaboratively with each other and with specialist colleagues.

However, in reality the role of general practice in palliative care for children currently varies widely, from very little involvement to a much more proactive role in holistic care, with some GPs providing out-of-hours medical care or medical cover in children's hospices[32].

It may help to engage and empower GPs to have a more active role in supporting children with life-limiting conditions and their families if they are included more fully and at an earlier stage when a child is diagnosed with a life-limiting or life-threatening condition. Some specific practical approaches can foster closer links between families and their GP, such as carrying out joint home visits or appointments. We call on NHS England to help increase the profile of children's palliative care in primary care – and work with partners including Health Education England to improve education and training for GPs in identifying children who need palliative care as early as possible.

NICE[33] recommends that specialist paediatric palliative care teams should include

---

[31] Nursing and Midwifery Council. 2018. Standards for Nurses. Available to download from: http://bit.ly/2KhJlTX

[32] Neilson, S, Gibson, F & Greenfield, S. 2015. Pediatric oncology palliative care: Experiences of general practitioners and bereaved parents. Paediatric Palliative Care and Medicine 5:214.

a pharmacist with expertise in specialist paediatric palliative care at a minimum. It is therefore vital that pharmacy is commissioned locally – and that NHS England holds STPs, ICS and CCGs to account for the way in which they do so.

3.8 How can digital technology help the NHS to: a) Improve patient care and experience? b) Enable people and patients to manage their own health and care? c) Improve the efficiency of delivering care?

and

3.11 How do we ensure we don't widen inequalities through digital services and technology?

A key element of children's palliative care is supporting children, young people and their families to develop ACPs which set out their wishes for current care and treatment in the future. These are often well received if they are introduced early as a plan for life, enabling the family to plan with professionals for their child's care during intermittent potentially reversible health deteriorations, preparing the way for decisions around irreversible changes at the end of life. ACPs should be regularly updated and shared with everyone involved each time they are updated. A parallel planning approach is very helpful to enable children and families to plan for hopes and wishes for life as well as advance plans for their end of life care.

We call on NHS England to explore ways of using digital technology to enable families to store, update and share their ACPs with other individuals and organisations involved in commissioning and providing the care they receive. This should make sure that families have the option to include their ACPs as part of an integrated plan, such as an education, health and care (EHC) plan.

All families should be signposted to relevant sources of local and national support[34] This may mean that written or digital resources should be provided or that time needs to be set aside to discuss options with the family. Interpretation services and translated materials should be provided to those families whose first language is not English.

Age and developmentally appropriate resources should be provided for children. Care should be taken that information is accurate, up-to-date and of good quality (for example, check that materials have the Information Standard kitemark).

This is important given the range of information of variable quality available to families online.

3.11 How can we increase opportunities for patients and carers to collaborate with the NHS to inform research and also encourage and support the use of proven innovations (for example new approaches to providing care, new medical technologies, use of genomics in healthcare and new medicines)?

Children's palliative care is a relatively new field in which the development and delivery of services has outstripped the evidence base[35]. More quality research is needed not only to

---

33 The National Institute for Health and Care Excellence. 2016. End of life care for infants, children and young people with life-limiting conditions: planning and management - NICE guideline [NG61]. Available to download from: http://bit.ly/2ODg2hY

[34] In England, law stipulates that all local authorities must publish a local offer of all commissioned statutory and voluntary sector services providing support to disabled children and families.

[35] Bluebond-Langner, M et al. 2014. Pediatric palliative care in 2014: Much accomplished, much yet to be done. *J of Pall Care 30th Anniversary Thematic Issue*, 30,4,311-316.

identify and document the issues patients, families and professionals face and the circumstances in which they arise, but also to guide the development and evaluation of interventions to address these issues. Such research is key to providing the best support for an ever increasing and diverse population of babies, children and young people with life-limiting and life-threatening conditions.

A number of recent research prioritisation exercises have been carried out[36],[37],[38],[39]. Parents, patients, researchers and clinicians who have participated in these exercises have identified five areas where further research is needed:

- the illness and bereavement experience
- communication and decision-making
- emotional, social, and psychological wellbeing
- pain and symptom management
- service development and delivery, including the development of outcome measures.

Research in the context of children's palliative care is complex. It involves capturing the views of children and young people, parents, clinicians and the institutions of which they are a part and needs to reflect these views honestly and dispassionately, irrespective of whether they differ from those of the researcher or current clinical practices.

As a small field, it's important to involve a variety of partners in research who have a breadth and depth of expertise not just for the delivery of large multi-site studies, but also to facilitate the complex, robust studies that are needed to advance the evidence base for the children's palliative care sector as a whole.

Researchers need a broad ranging methodological toolkit to ensure that the method used best fits the nature of the study being undertaken. For example, ethnographic and child and family-centred methods can be used to better capture the voices of children and families; observational studies can usefully draw on routinely collected clinical data to supplement data that is collected for research purposes. There is a need to do more prospective studies in order to focus on the reality of the situation being studied as it unfolds. It may be feasible to use randomised control trials to evaluate new pain management interventions and protocols versus existing approaches. Systematic reviews of the literature including Cochrane reviews are a useful first step in establishing what is known and where the gaps are on a given issue as well as in synthesising existing knowledge as we look to develop evidence-based guidance.

As well as developing a wider programme of research questions, it is equally important to think about how to enable children and families and people working in the children's palliative care sector to become actively involved in carrying out research. There are three

---

[36] Steele, R et al. 2008. Research priorities in pediatric palliative care: A Delphi study. *Journal of Palliative Care* 24(4): February 2008, 229-39.

[37] Baker, J et al. 2015. Research priorities in paediatric palliative care. *J of Paediatrics,* Vol 167, Issue 2, Aug 2015, pp 467-470

[38] Downing et al. 2015. Priorities for global research into children's palliative care: results of an International Delphi Study. *BMC Palliative Care* 14(1):36 · August 2015

[39] Martin House. 2017. Research Prioritisation Exercise. https://www.york.ac.uk/healthsciences/research/public-health/projects/martinhouse/projects/prior-exercise/

major barriers to conducting robust research in children's palliative care: (1) funding (2) research governance (3) clinician gate keeping.[40]

There are significant barriers to securing research funding. Relatively small numbers, diverse illnesses and conditions make competing for and securing research funds difficult; a situation exacerbated by the limited number of funders both private and public. The children's palliative care research community can learn from what has worked well in other fields with small populations who have formed national, European and global research networks and consortia to pool numbers and expertise so that studies are more robust and have sufficient power to determine effects.

The difficulty of securing ethical approval to carry out research with children, young people and their families with life-limiting conditions has been a significant barrier and additional training for ethics committee members may be needed. There are positive signs that some NHS ethics committees now put themselves forward as having specific expertise in children's studies and there is a growing awareness that children and families themselves want to participate in research studies, with a move towards co-design and co-research with service users.

A key step in enabling research participation is to give children with life-limiting conditions and their families the same right as anyone else to decide if they wish to participate in sensitively conducted research. Ethics committees now welcome 'patient' representatives to attend committee meetings with members of the research team. Hearing the child and family perspective can be very powerful in alleviating any concerns that the ethics committee may have about the importance of the question or the additional 'burden' that participation in a study may place on children and their families. Researchers in children's palliative care are also beginning to look at strategies such as 'opt out' which are successfully employed in other fields and settings (for example, emergency medicine, adult palliative care) for particular kinds of research.

Following a submission from the joint Together for Short Lives and Association for Paediatric Palliative Medicine Research Group, the latest RCPCH Guidance on involving children in medical research[41] includes a section on enabling research with particularly vulnerable children which states that:

> *"Children with life-threatening illnesses, looked-after children, their families, and bereaved families require a robust evidence base for both physical and psychosocial aspects of care. However, evidence remains limited and largely focused on aspects such as symptom relief. The fear of intruding on children who are especially vulnerable, and their families, and the perceived need to provide them with extra protection has led to reluctance to involve them in research. However, there is now considerable evidence that families and young people who participate in research find it beneficial rather than harmful, with opportunity to speak about illness and death, express painful emotions, and obtain release from isolation. There is also evidence of a 'maturational effect' of life-ending illnesses, where children and young people express a wish to benefit others and benefit themselves from such 'meaningful' encounters. Research in these sensitive areas, including qualitative studies, requires review by research ethics committees that have the necessary knowledge and expertise."*

---

[40] Beecham, E et al. 2016. *A call for increased paediatric palliative care research: Identifying barriers. Palliative Medicine*, 30,10 page 979-980.

[41] Modi, N et al. (2014). *Guidance on clinical research involving infants, children and young people: an update for researchers and research ethics committees*. RCPCH page 6.

Other ways to reduce barriers to participation include:

- involving clinicians in the design and development at the outset
- holding regular meetings to discuss the recruitment of participants
- embedding researchers in clinical teams
- pressing for changes in research governance such that researchers can carry out invitation and recruitment themselves, rather than through clinicians.

Quality research takes time and cannot easily be fitted in on top of an already packed clinical brief. This needs to be recognised so that the views of clinicians and those on the front line of service delivery can contribute in a timely way to research and be involved in grant applications and publications.

Collaboration is key between clinicians and service providers and with academic researchers. It is important that research questions are discussed early and framed in the context of what is most important for the sector. Such collaboration also contributes to the development of a research-ready workforce by building the capacity of professionals with sufficient skills and experience to conduct large scale and robust children's palliative care research. There is a pressing need to develop and support the next generation of researchers through graduate programmes, fellowships and academic posts.

Collaborations between clinicians and academics will contribute to a research ethos in children's palliative care in which not only the conduct of research, but also the findings from that research will find their way into practice. It will lead to a balance between eminence based and evidence-based practice.

3.16 How can the NHS encourage more people to share their experiences in order to provide an evidence base for checks on whether changes introduced under the long term plan are driving the changes people want and need?

We agree with CLIC Sargent, the National Children's Bureau, the Office of the Children's Commissioner, the Royal College of Paediatrics and Child Health and the Children's Society that children, young people and their parents and carers, must be central to collaborating and the coproduction of a cohesive NHS England child health strategy. The benefits of involving children and young people when designing quality health services are already well evidenced. Involving children and young people in their own care improves outcomes and can potentially yield efficiency savings for the system. It is extraordinary that, in so many parts of the NHS and wider health system, adults fail to take account of children and young people's views when measuring their health outcomes. NHS England can play a key role in driving culture change in services by involving children, young people and their families in the development of a NHSE child health strategy, the ongoing planning and shaping of services and their evaluation.

3.17 How can the NHS improve the way it feeds back to people about how their input is shaping decisions and demonstrate that the NHS is the world's largest learning organisation?

We call on the NHS to work with organisations like Together for Short Lives which can offer important channels with which to communicate with people who use the NHS, including those who may be hard to reach.

For more information, please contact:

James Cooper
Public Affairs and Policy Manager
0117 989 7863
07415 227 731
james.cooper@togetherforshortlives.org.uk

Lyndon Ashmore
Campaigns Officer
0117 989 7866
lyndon.ashmore@togetherforshortlives.org.uk