



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.

Compendium of Local Solutions for Children's Palliative Care
January 2018

Introduction

This compendium complements Together for Short Lives' report "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"¹. The overview was supported by NHS England, to provide a baseline of the current position of the children's palliative care sector in providing high quality, equitable palliative and end of life care based on that guideline. Data was collected from the chairs, or their representative, of the regional children's palliative care networks (appendix 1) and was then collated and analysed against the NICE guideline.

The results showed a mixed level of achievement reflecting the wide variation that exists across each of the networks. Using the data and these results, a series of charts were developed to allow an exercise for networks to benchmark against each other.

Whilst talking to services when collecting the data, and through our links with the networks and services we have been made aware of the practical solutions to care challenges that many have developed. Therefore, we invited the networks to share their local solutions (Appendix 2) and those solutions form this compendium

This is not designed to be a static document. We hope that the networks continue to add to it, as they address problems, develop new solutions and share that learning with others to improve systems and services to benefit children, families and those that support them.

Jane Houghton, Together for Short Lives, January 2018

¹ http://www.togetherforshortlives.org.uk/professionals/resources/12497_together_for_short_lives_report_to_nhs_england

Index of Local Solutions

The Local Solutions are linked through the index to the recommendations of the NICE Guideline “End of life care for infants, children and young people with life-limiting conditions: planning and Management” (2016).²

	Page
1.1 General principles	
Transition	
Transition team	6
Neonatal	
Perinatal Service Forget Me Not Children’s Hospice	7
Communication	
Weekly Multi- Disciplinary Team teleconferences	9
Journeys, Children’s palliative care - a resource for professionals.	10
1.2 Care planning and support throughout the child or young person’s life	
Advance care plans	
National Anticipatory Care Plan for Babies, Children and Young People	12
Database for Children and Young People Anticipatory Care Plans	13
Emotional and psychological support and interventions	
Helping siblings of Life Limited and Life Threatened children.	14
Access to psychology services for families	15
1.3 care of the child or young person who is approaching the end of life	
Managing distressing symptoms	
Out of hours cover for local hospice	17
Peer support via WhatsApp for doctors	18
Out of hours medical support to CCNs provided by hospice medical director	19
Rapid transfer	
Intensive care transport across all age groups	20

² (<https://www.nice.org./guidance/ng61>)

Preferred place of care and place of death

Team of Diana Children’s Nurse to cover Scottish Health Board areas	21
Care 24 to enable 24hr End of Life care	22
Just in case box guidelines.	23

1.4 Care and support for parents, carers and healthcare professionals in relation to the death of a child or young person

Care after death

Inter-professional communication of death of a Baby, Child or Young Person	25
--	----

Bereavement support

Children’s bereavement team	26
-----------------------------	----

1.5 Service delivery

Multi- Disciplinary Team

Wide range of Health Care Professional roles working together on network	28
--	----

Specialist paediatric palliative care team

Partnership between NHS and hospice to fill level 6 post	29
Integrated palliative care service across all departments in tertiary children’s hospital	30
Funding level 4 consultant	31

Commissioning

Bespoke expert advice to localised and specialised commissioning	32
--	----

Facilities

Quiet room at Isle of Man airport	33
A safe haven within a children’s hospital	34

Training

Regional education day/event	35
Satellite education programme	36

Service provision

Identifying gaps across the regional network area	37
---	----

Appendix 1 NICE Guidelines for CPC service data collection questions	38
---	----

Appendix 2 NICE Guidelines: Local Solutions Proforma	40
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1.1 General principles

Transition

Name of the solution	Children's Hospices Across Scotland (CHAS) Transition Team	
Problem it was aiming to solve	Young People with Palliative needs requiring age appropriate palliative care services and respite.	
Describe how the solution was implemented	<p>Dedicated team establish by CHAS through Big Lottery funding to support young people and their families through a three-year transition process from children's services to adult services.</p> <p>Anticipatory Care Planning is key to the process ensuring Young People transition have an agreed plan for future needs.</p> <p>Lobbying of politicians and Scottish Government has taken place by CHAS and directly by some of the Young People to raise awareness of this new need as young people live longer with their palliative conditions.</p>	
Pros and cons and reflections	<p>Pros</p> <ul style="list-style-type: none"> • collaborative work continues with Adult Hospices and Local Authorities to identify age appropriate service requirements <p>Cons</p> <ul style="list-style-type: none"> • Continues to be inadequate services for Young People to transition to 	
Network	Scotland	
Contact details	Name Caroline Porter Diana Children's Nurse - West of Scotland	Email carolineporter@chas.org.uk

Perinatal

Name of the solution	Perinatal Service Forget Me Not Children's Hospice
Problem it was aiming to solve	Traditionally hospices have provided care for children who are born with Life Limited Conditions. With earlier diagnosis in the womb and significant numbers of babies not surviving the pregnancy or for a very short of time after delivery, it was identified that a gap in provision for these families going through such a distressing time was being unmet and unsupported apart from the acute hospital staff. Distressed families had very little external support and time with their baby away from the acute setting when they needed it the most
Describe how the solution was implemented	The perinatal service was initially set up to support families at the immediate point of delivery, an in-reach service was set up to work alongside clinicians in the acute sector to offer support to families and clinicians. Whilst offering bereavement support to these early neonatal deaths we very quickly realised that this support was needed far earlier, as early as a diagnostic 20-week scan. So, although neonatal nurses were employed as a start to support the neonatal phase, and are still a requirement in the service, the care needed during pregnancy, for siblings and post death was clearly needing more intervention. To meet this need the service was extended and a midwife with experience in bereavement and care staff were appointed to extend the service to support the whole family through the whole journey alongside the neonatal nurses. Working with fetal medicine, neonatal and midwifery teams the service has developed to provide collaborative working on pathways that the whole family benefit from.
Pros and cons and reflections	<p>Pro's –</p> <ul style="list-style-type: none"> • holistic care of families • making a difference in the most traumatic of circumstances. • Families are more aware of their choices • Collaborative working, all professionals working on same pathway wherever the family are • Families have time memory making throughout pregnancy and beyond • Families have some joy out of such tragedy • Dispelling the myth around paediatric palliative care and what children's hospices offer <p>Con's –</p> <ul style="list-style-type: none"> • Volume and rapid growth can be difficult to control • Challenge to get accepted into some departments • Intense emotional demand on the team • Families returning with differing types of emotional challenges e.g. months post bereavement, struggles of having sat with dead child etc
Lessons learned	<ul style="list-style-type: none"> • Have all paperwork, pathways ready at beginning even if likely to change

	<ul style="list-style-type: none"> • Have clearly defined protocols around limitations of acceptance, taking babies at 24-week gestation or having died in utero can be a challenge to some of the team so be realistic and think of team as well as families • Bereavement midwife is a must as early as possible in service offering • Team resilience and emotional support needed from the beginning (both formal and informal) 	
Network	Yorkshire and Humber	
Contact details	Name Sharon Burton Director of Care	Email sharon.burton@forgetmenotchild.co.uk

Communication

Name of the solution	Managed Service Network for Children and Young People with Cancer (MSNCYPC) Palliative Care Weekly Multi- Disciplinary Team (MDT) teleconferences	
Problem it was aiming to solve	Children in Scotland receive treatment for cancer in a range of tertiary, secondary and primary care settings. For those children receiving shared care in different settings it was important to improve communication between centres.	
Describe how the solution was implemented	Weekly teleconference MDT meetings take place to discuss those children with a deteriorating palliative diagnosis or active disease progression without curative option. Each participant has the opportunity to discuss a case or contribute to the discussion of others. The third week of the month is designated as an educational opportunity with each centre rotating to present as a case study.	
Pros and cons and reflections	<ul style="list-style-type: none"> • Attendance is variable and generally medically orientated. • More MDT attendance would be beneficial to discuss children in a more holistic manner. • Caseload capacity appears to limit nursing representation. • AHP and Social Work representation should be encouraged. 	
Lessons learned	Dedicated administrative support from the MSNCYPC supports the more effective running of the teleconference.	
Network	Scotland	
Contact details	Name Caroline Porter Diana Children's Nurse - West of Scotland	Email carolineporter@chas.org.uk

Communication

Name of the solution	Journeys, Children's palliative care - a resource for professionals. www.chipac.uk	
Problem it was aiming to solve	<ul style="list-style-type: none"> • TEDDY project (Training and Education Developed for the Delivery of Care to Young People in the Communities across Greater Manchester: The Children's Palliative Care Project), a Department of Health funded programme highlighted the lack of documentation and standardisation across the North West • A universal approach was identified as a need • Integration of services despite condition or geographical location • A more practical approach to the delivery of palliative care • To improve the interface between generic services and specialist palliative care services 	
Describe how the solution was implemented	<ul style="list-style-type: none"> • Early days still. • Need for resource identified. • Gathered information that would be necessary. • Website developed with specialists input into relevant sections. • Peer reviewed and edited/amended. • Ratification from Network to endorse website. • Communication strategy; providing training across Acute Children Community Nursing Teams, voluntary sector, acute trusts in Greater Manchester • Raised profile within the North West Children's Palliative Care Network and presenting at national children's palliative care conferences. 	
Pros and cons and reflections	<p>Pros</p> <ul style="list-style-type: none"> • Positive feedback from relevant professionals. • Standardised approach to documentation. • Promoted best practice/recommendations to care across the Greater Manchester footprint. <p>Cons</p> <ul style="list-style-type: none"> • Difficult to allocate time to update/edit website. • Issues with website, problems accessing it. • Maintenance of website. 	
Lessons learned	<ul style="list-style-type: none"> • Needed Neonatal input. • Good IT support. • Effective communication strategy. • Administration support to maintain and keep up to date. 	
Network	North West	
Contact details	<p>Name</p> <p>Anna Oddy, Children's Complex Care Coordinator and Palliative Care Specialist Nurse</p>	<p>Email</p> <p>Anna.oddy@nhs.net</p>

1.2 Care planning and support throughout the child or young person's life

Advanced Care Plans

Name of the solution	National Anticipatory Care Plan (ACP) for Babies, Children and Young People (Health Improvement Scotland (HIS)) – IN PROGRESS	
Problem it was aiming to solve	Standardise ACP format for this age group. Work initiated through HIS and through the ACP Programme Board in response to Scotland’s Strategic Framework for Action commitments	
Describe how the solution was implemented	<ul style="list-style-type: none"> • Meeting of professional representatives with experience in the use of existing ACPs from a range of Health Boards across Scotland and Children’s Hospices Across Scotland (CHAS). Led by HIS • Review of current formats. Significant conversations as to appropriate formatting, language, and capacity of adult ACP to be transferable • Currently developing ACP guidance for staff and leaflet for families • Currently looking at various platforms for staff awareness and education • Currently looking at funding streams to support roll-out and education 	
Pros and cons and reflections	<p>Pros: -</p> <ul style="list-style-type: none"> • Various professionals have long been looking for a Scottish template that will be recognised across all locations as many BCYP use Tertiary services <p>Cons: -</p> <ul style="list-style-type: none"> • HIS/ACP Programme Board found it difficult to recognise that an adult model modified would not be fit for purpose, and that a lot of info is already supported through GIRFEC assessment and child’s plans • took a long time for right people to be brought to the table • nominated persons from HIS were pulled back to cover other work 2 months before final version approved and then roll out of consultation 	
Lessons learned	<ul style="list-style-type: none"> • HIS were delivering on this with monies allocated for the adult ACP. The needs of BCYP need to be acknowledged fully within each working stream of the Strategic Framework for Action. Length of time to completion influenced their capacity to continue in their original positions. It was not made clear that funding to roll out the Strategy had to be sought independently • Identify the correct people around the table from beginning 	
Network	Scotland	
Contact details	Name: Fiona Reid Diana Children’s Nurse, North Scotland	Email: fionareid@chas.org.uk

Advanced care plan

Name of the solution	Databases for Children and Young People’s Acute Deterioration Management plan (CYPADM) and Anticipatory Care Plans (NHS Grampian and NHS Highland)	
Problem it was aiming to solve	Record of all current and expired forms. Timely reminders to responsible professionals for review. Standardised distribution pathway. Useful for audit purposes	
Describe how the solution was implemented	Based on the database model already in use in NHS Lothian <ul style="list-style-type: none"> • Identification of administrator • Development of database • Education of professionals likely to be completing Anticipatory Care Plans and/or CYPADMs 	
Pros and cons and reflections	<p>Pros</p> <ul style="list-style-type: none"> • Raising awareness of ACP and CYPADM processes • Responsibility for, and standardised distribution of forms from a single central point <p>Cons</p> <ul style="list-style-type: none"> • system has proved difficult to manage unless a 2nd administrator can be trained to cover • finding money from budgets to get OT to develop resource, and write in to job plans <p>Reflection</p> <ul style="list-style-type: none"> • despite the negative points this action has significantly raised awareness of the whole ACP potential 	
Lessons learned	As an employee of a hospice organization, it has been incredibly difficult to get the ‘buy in’ of NHS teams, and make recommendations for allocation of budgets	
Network	Scotland	
Contact details	Name Fiona Reid Diana Children’s Nurse, Scotland	Email: fionareid@chas.org.uk

Emotional and psychological support and interventions

Name of the solution	Helping siblings of children with life limiting conditions:- Sirona Health and Care Lifetime Sibling Group	
Problem it was aiming to solve	Research literature and clinical evidence highlights that siblings of children with life limiting and life-threatening illnesses may at times experience feelings that are difficult to express. The groups are aimed at helping siblings express their feelings and find positive ways of coping.	
Describe how the solution was implemented	Sibling groups were offered and delivered to siblings of children referred to the service and who were identified by Nurses, Psychologists or parents to have a need for support. Groups involved a sequential programme of activities spread over two days in a safe, fun and creative environment. The aims were to: offer information about their siblings' condition and identify misconceptions; exploration and expression of feelings and their impact on them and their family; normalisation of feelings and sharing experiences of those children in similar situations; development of useful coping strategies and encourage the making of new friends. Activities were creative and fun and at the end of each group a feedback session with parents was offered, to enable a sharing of information and reflection of what had been gained by attending the group.	
Pros and cons and reflections	<p>Pros</p> <ul style="list-style-type: none"> • Feedback from siblings and parents highlighted that the group had met the aims and intentions highlighted above. <p>Cons</p> <ul style="list-style-type: none"> • Small numbers and recruitment difficult <p>Reflections from staff</p> <ul style="list-style-type: none"> • lovely experience to get to know the siblings and understand the psychological impact for family members/highlighted importance of normalisation and shared experience for siblings. 	
Lessons learned	<ul style="list-style-type: none"> • The groups are a valuable way to offer psychological support to siblings. • Able to reach a population which may be difficult to reach/engage. • Most insights and therapeutic work happens when activities are fun and use creative tools. • Some children used this as an opportunity to share important messages with parents at the end of the group, which was useful information to parents about how their son/daughter was feeling, which may not have happened otherwise. • Recruitment was difficult in terms of maximising opportunities to attend which does not coincide with school/holidays booked when offered in half-term. • Recognition of need to increase awareness and promotion of the groups – possibly through the South West Network. 	
Network	South West	
Contact details	Dr Lucy Davis, Clinical Psychologist,	Lucy.Davis@sirona-cic.org.uk

Emotional and psychological support and interventions

Name of the solution	All families living in Newham in which there is a child (0 to 19 years) who is not expected to live into adulthood are offered access to psychology service. This includes families who have been bereaved through the death of a child from a life-limiting condition	
Problem it was aiming to solve	<p>To reduce distress and enhance quality of life for children who are not expected to live in to adulthood.</p> <p>To support the families of children with life limiting conditions to build resilience and cope with the psychological aspects of caring for their child and enable them to create positive memories of their time with the child.</p> <p>To provide early intervention to reduce risk of development of severe mental health problems.</p> <p>To support the family and multiagency team around the child to develop collaborative working relationships towards minimizing the potential negative impacts of the child’s health needs on all members of the family.</p> <p>To enable families (parent/carers, siblings and significant others) to find ways to go on in their lives and remember their child after the death of the child.</p>	
Describe how the solution was implemented	<p>Any member of the family (adults and children) can access psychology appointments (individually or together) for support, assessment and therapeutic intervention in relation to the impact of the child’s life limiting condition, symptoms, medical interventions, dying and death on thoughts, feelings, behavior, day-to-day functioning/coping and relationships.</p> <p>Psychological and Systemic Consultation is also offered to the wider multiagency team around the child and family (primary, secondary and tertiary health service, education, social care and third sector organisations involved in their care) to enable families and services to develop collaborative working relationships and work together to improve quality of life for the child and family. The service is based within the Diana service as the Diana Children’s Community Child and Family Clinical Psychology Service</p>	
Network	London	
Contact details	Name Amy Volans, Lead Clinical Psychologist & Family Therapist	Email Amy.volans@nhs.net

1.3 Care of the child or young person who is approaching the end of life

Managing distressing symptoms

Name of the solution	Out of Hours Medical Cover for local Hospice	
Problem it was aiming to solve	Lack of medical cover out of hours and at weekend for children attending the hospice for Short Breaks	
Describe how the solution was implemented	Agreement between the Children's hospital and local hospice that out of hours, the on-call general paediatric team would accept calls from the Hospice team for any clinical concerns. Children may require transfer to the hospital for assessment unless advice can be given over the phone.	
Pros and cons and reflections	<p>This is only a recent service so maybe too early to assess outcomes.</p> <p>Pros</p> <ul style="list-style-type: none"> • There is 24-hour medical advice for the children • Hospice and hospital working in partnership and developing relationships <p>Cons</p> <ul style="list-style-type: none"> • medical advice is not on site and children may be transferred to hospital for assessment unnecessarily • Access to medical information maybe limited as not all children are known to the children's hospital 	
Network	North East	
Contact details	Name: Alison Guadagno, Consultant Paediatrician	Email Alison.guadagno@nuth.nhs.uk

Managing distressing symptoms

Name of the solution	Real time peer support for doctors across the region via WhatsApp	
Problem it was aiming to solve	There was no regional level 4 consultant to give advice to level 3 doctors who needed real time peer support and advice with difficult and complex symptom management	
Describe how the solution was implemented	The doctors in the region looked at possible ways of communicating effectively with each other to get real time advice and support. Most methods were not practical, but they found a WhatsApp group worked and met their needs. WhatsApp has a group chat feature which allows you to either send the same message to multiple contacts without typing it again and again, and have conversation with a group of friends. In this example a doctor can send a query and receive replies, support and advice in real time from other doctors who belong to the group	
Pros and cons and reflections	<ul style="list-style-type: none"> • It is not always ideal, but it is meeting a need at present anyway and is better than having nothing in place. • People are pleased with this system 	
Network	West Midlands	
Contact details	Name Nicki Fitzmaurice , Deputy Head of Nursing Corporate Nursing, Lead for Palliative and Bereavement Care Services	Email Nicola.fitzmaurice@bch.nhs.uk

Managing distressing symptoms

Name of the solution	Out of hours medical support to Children's Community Nurses (CCNs) provided by hospice medical director	
Problem it was aiming to solve	The CCN teams had nobody to give them specialist medical advice out of hours. There was no level 4 consultant in the area and limited level3 to give them the necessary advice. Without the necessary advice and support, children may have had to be admitted to hospital	
Describe how the solution was implemented	The Birmingham Clinical Commissioning Group (CCG) recognised the needs of children receiving palliative care. The CCG looked at options to keep children at home with CCN support and agreed to commission the support given by the hospice doctor to the CCNs, in a formalised way.	
Pros and cons and reflections	<p>Pros</p> <ul style="list-style-type: none"> • The need for hospital readmission for palliative care children reduced. • Safe service from CCNs • More confident CCNs <p>Cons</p> <ul style="list-style-type: none"> • Inequalities of service as other areas do not commission this service • Medical advice given with good will rather than officially to these areas 	
Network	West Midlands	
Contact details	Name Mark Hunter, Consultant Paediatrician	Email Mark.hunter@acorns.org.uk

Rapid Transfer

Name of the solution	Intensive care transport for babies and children,	
Problem it was aiming to solve	<p>Paediatric Intensive Care Units and Neonatal Intensive Care Units had their own transport system.</p> <p>KIDS is an acute transport and advice service for the management of critically ill children requiring intensive care in the West Midlands. Neonatal Transport Service is a dedicated transfer service moving babies between neonatal units in the West Midlands. They were separate services but now are one system and team for both neonates and children</p>	
Describe how the solution was implemented	Working with the Ambulance service, it was recognised that was a need for one service to allow more flexibility and efficiency for the benefit of the babies and children. The 2 systems therefore merged.	
Pros and cons and reflections	<p>Cons</p> <ul style="list-style-type: none"> • End of Life care is not commissioned but exists through the willingness for professionals to go beyond the boundaries to allow for choice of place of death at end of life and rapid transfer to that place. 	
Network	West Midlands	
Contact details	<p>Name</p> <p>Nicki Fitzmaurice, Deputy Head of Nursing Corporate Nursing, Lead for Palliative and Bereavement Care Services</p>	<p>Email</p> <p>Nicola.fitzmaurice@bch.nhs.uk</p>

Preferred place of care and place of death

Name of the solution	A team of Diana Children’s Nurses (DCN) in place , covering Scottish Health Board areas	
Problem it was aiming to solve	Earlier recognition of Baby, Children and Young People’s palliative needs in the acute services and community settings	
Describe how the solution was implemented	<p>Children’s Hospices Across Scotland (CHAS) Diana Children’s Nurses x 3 working across Scottish Health Board areas to provide strategic influence, workforce development, quality improvement and clinical leadership and expert practice.</p> <p>Weekly presence in Neonatal Intensive Care Units (NICU), Paediatric Intensive Care Units (PICU) and paediatric wards. End of Life choices provided to families in PICU/NICU/wards to transfer to home or hospice. Compassionate extubation coordinated and facilitated working with all teams involved across all settings.</p> <p>Extensive education and training sessions delivered to Medical, Nursing, Allied Healthcare Professionals, Social Services professionals via a range of platforms and techniques. Filmed PowerPoint presentations have been recorded by the NHS Education for Scotland Remote and Rural Health and Education Alliance allowing professionals to download DCN educational sessions at a time suitable to them.</p>	
Pros and cons and reflections	<ul style="list-style-type: none"> • Each DCN has a specific remit. DCN East: Neonatology, DCN North: Community, DCN West: Oncology and PICU however all have a generic responsibility for developing palliative services within their geographical location and across many specialities other than just their specific area. • Employed by CHAS but with the focus of working within and alongside the NHS, Local Authority and other third sector services. • Most progress has been made in the specialisms concentrated on by the DCNs in their geographical location. Equity across all geographical locations has been dependant on capacity. 	
Lessons learned	An independent evaluation of the service recommends capacity should be increased to enable DCN specialisms or nurses with similar skills to roll out across the whole country.	
Network	Scotland	
Contact details	Name Caroline Porter Diana Children’s Nurse, West Scotland	Email carolineporter@chas.org.uk

Name of the solution	Care 24 to enable 24 hr End of Life Care	
Problem it was aiming to solve	To enable 24-hour end of life care at home for Baby, Children and Young People with a palliative diagnosis in NHS Lothian.	
Describe how the solution was implemented	NHS Lothian Community Children’s Nurses (CCNs), Clinical Nurse Specialists and Paediatric Oncology Outreach Nurse Specialists (POONS) provide Office Hours support to children in their own homes at end of life. CHAS provide a telephone service for the families in the out of hours period with the agreement that a home visit from CHAS staff could be facilitated, out of hours, in a changing or deteriorating situation.	
Pros and cons and reflections	<p>Cons</p> <ul style="list-style-type: none"> • Capacity issues experienced by all teams at times. • Clear lines of Medical responsibility are required <p>Pros</p> <ul style="list-style-type: none"> • Daily communication template between teams is circulated by CCNs 	
Lessons learned	<p>Concept is excellent, and options are being explored in the West of Scotland regarding how a similar service can be offered. This service aims to have a shared rota for out of hours cover between CCN’s and CHAS. This will require contractual commitment from Specialist Children’s Services to enable a core team of CCN’s to work out of hours in collaboration with CHAS and the POONS when appropriate.</p> <p>Currently in the West of Scotland POONS offer a 24 hour on call service to provide end of life care at home for a child with a cancer diagnosis.</p>	
Network	Scotland	
Contact details	Name Caroline Porter Diana Children’s Nurse, West Scotland	Email carolineporter@chas.org.uk

Preferred place of care and place of death

Name of the solution	Managed Service Network for Children and Young People with Cancer (MSNCYPC) Palliative Care Steering Group Just in Case box guidelines	
Problem it was aiming to solve	No national guidance available for oncology and community teams regarding the supply, stock and rationale for Just in Case boxes in the home setting when providing end of life care.	
Describe how the solution was implemented	<p>Guidance was developed through a Short Life Working Group of Nursing, Pharmacy and Medical professionals. This will be launched by the MSNCYPC and sessions are planned to be delivered in the 5 paediatric oncology centres across Scotland.</p> <p>The guidance was developed for oncology and haematology but always with the aim that it would be equally transferable for non-oncology children.</p> <p>The guidance will be available on the NHS Education for Scotland Managed Knowledge Network website and will be discussed and circulated via Scotland's Children and Young People Palliative Care Network in March 2018.</p>	
Pros and cons and reflections	<ul style="list-style-type: none"> • Some delay in timeframe from development to launch. • Still some debate regarding the inclusion/exclusion of naloxone. • Will need reviewed within 6-12 months to amend if required once trialled in practice. 	
Lessons learned	Important to have made them relevant to non-oncology children from the outset.	
Network	Scotland	
Contact details	Name Caroline Porter Diana Children's Nurse, West Scotland	Email carolineporter@chas.org.uk

1.4 Care and support for parents, carers and healthcare professionals in relation to the death of a child or young person

Care after Death

Name of the solution	Inter-professional communication of the death of a Baby, Children and Young People protocol (NHS Highland)	
Problem it was aiming to solve	Improve the timely communication of an Intrauterine death, still birth, death of neonate, baby, child or young person Prevention of inadvertent phone calls, recall for clinics or immunisation programmes. Prepare delivery teams/professionals working outside the acute setting	
Describe how the solution was implemented	Use and collation of pre-existing but out of date tools used locally Short Life Working Group through engagement of midwifery, neonatal, children's unit, community nurses, specialist children's nurses, consultants, Social Workers, additional support needs for schools development officer, GPs, Accident & Emergency Department staff, child health admin, e-health Development of paper and electronic resource for referral to be held across all relevant areas (multiple versions) Presentation to Nurses, Midwives and Allied Healthcare Professionals Committee and GP sub-committee for approval	
Pros and cons and reflections	<p>Pros</p> <ul style="list-style-type: none"> • engagement of a lot of teams to draw together one document • encourages teams to think beyond notification within just the acute setting and conventional GP/HV in primary care (e.g. contact nutrition/oxygen suppliers, school transport escort, community pharmacy, voluntary/charity teams) <p>Cons</p> <ul style="list-style-type: none"> • trying to cover every death scenario across the full age range and types of death (palliative, acute, suspicious) • the number and slow process of following through the bureaucracy 	
Lessons learned	<ul style="list-style-type: none"> • Lower expectations as to pace of achieving outcomes • Identify a Lead from NHS to take forward as the pace is impacted by developer coming from external organisation 	
Network	Scotland	
Contact details	Name: Fiona Reid Diana Children's Nurse, North Scotland	Email: fionareid@chas.org.uk

Bereavement support

Name of the solution	Child Bereavement UK(CBUK) Service in NHS Greater Glasgow and Clyde (NHSGGC)	
Problem it was aiming to solve	No bereavement service available to staff or families for a 3-year period in NHSGGC	
Describe how the solution was implemented	<p>CBUK have been appointed a three-year contract funded by Glasgow Children’s Hospital Charity to deliver a bereavement service to families and staff within NHS Greater Glasgow and Clyde (NHSGGC).</p> <p>This service will work directly with families in the pre-bereavement period and will provide support as required following the death of a child. The service equally will focus on staff support and will offer a 24-hour staff telephone service, individual drop in sessions, facilitation of team debriefs and reflections and educational sessions.</p>	
Pros and cons and reflections	<ul style="list-style-type: none"> • Initially scoping exercise by hospital steering group recommended a service managed and delivered by NHSGGC. • Decision was ultimately taken to tender external providers for the service. 	
Lessons learned	It took 3 years to scope service requirements and then agree how this service would be funded and delivered. No universal interim service was available to families during this time other than the pre-existing charitable organisations specific to age and diagnosis.	
Network	Scotland	
Contact details	Name Caroline Porter Diana Children’s Nurse, West Scotland	Email carolineporter@chas.org.uk

1.5 Service delivery

Multi- Disciplinary Team

Name of the solution	Varied roles and specialities on network, linking children’s services with adult services, community services with inpatient services, statutory sector with charity sector.	
Problem it was aiming to solve	Links between all services to enable a seamless palliative care journey between all sectors and age groups for the children and their families	
Describe how the solution was implemented	<p>The roles on the network include those working with adults, those working across the region, those working across the sector, both statutory and voluntary.</p> <p>The network holds open meetings and all children’s palliative care professional groups and individuals are welcomed. The network is joint chaired by a GP, a lead hospital nurse and a hospice medical director. The attendees at the meetings include Children Community Nurses, community paediatricians, play specialists, researchers, hospice directors of care etc, and have even had a children’s author speak at one meeting. Each area of the region is represented and feeds into the meeting.</p>	
Pros and cons and reflections	<p>Pros</p> <ul style="list-style-type: none"> • Resources such as Anticipatory or Advanced Care Plans accepted widely across the region • Cooperation across the region • Sharing common aims and objectives and outcomes • All age groups from babies to young people included <p>Cons</p> <ul style="list-style-type: none"> • Long journeys for some to attend meetings • Time from clinical practice difficult 	
network	West Midlands	
Contact details	<p>Name</p> <p>Nicki Fitzmaurice, Deputy Head of Nursing Corporate Nursing, Lead for Palliative and Bereavement Care Services</p>	<p>Email</p> <p>Nicola.fitzmaurice@bch.nhs.uk</p>

Specialist Paediatric Palliative Care Team

Name of the solution	Partnership with hospice to fill level 6 post	
Problem it was aiming to solve	The hospital had a vacant level 6 post, but it proved difficult to fill as it was only part time. There was no more money to make it full time	
Describe how the solution was implemented	The hospice funds 2 days per week, making the post full time and therefore much more attractive. The post is now filled with the nurse working between the hospital and hospice.	
Pros and cons and reflections	<p>Pros</p> <ul style="list-style-type: none"> • Both the hospice and hospital gained a level 6 nurse so both benefited • The nurse gained useful experience in both places • The children benefit from continuity of care • The families see a familiar face in both places. 	
Network	West Midlands	
Contact details	<p>Name</p> <p>Nicki Fitzmaurice, Deputy Head of Nursing Corporate Nursing, Lead for Palliative and Bereavement Care Services</p>	<p>Email</p> <p>Nicola.fitzmaurice@bch.nhs.uk</p>

Specialist Paediatric Palliative Care Team

Name of the solution	Integrated palliative care service across the children's hospital	
Problem it was aiming to solve	Each department, across the trust was providing its own palliative care service leading to duplication, gaps, inequalities	
Describe how the solution was implemented	The trust has a palliative care lead nurse who negotiated with all the services to combine resources and training and form one service across the trust	
Pros and cons and reflections	<p>Pros</p> <ul style="list-style-type: none"> • More efficient in terms of staff and resources • Removed inequalities and so improved the service for all children needing palliative care • Same resources used, no matter which part of the hospital the child is • Better shared training 	
Network	West Midlands	
Contact details	<p>Name</p> <p>Nicki Fitzmaurice, Deputy Head of Nursing Corporate Nursing, Lead for Palliative and Bereavement Care Services</p>	<p>Email</p> <p>Nicola.fitzmaurice@bch.nhs.uk</p>

Specialist Paediatric Palliative Care Team

Name of the solution	Level 4 consultant funded and appointed to cover the tertiary hospital	
Problem it was aiming to solve	No children's palliative care consultant, level 4, at tertiary centre or in the region, to lead the CPC work	
Describe how the solution was implemented	Relationships and partnerships were developed between the trust, commissioners and charities as their aims dovetailed. A local charity has offered to initially funding the post, with expectations NHS commissioners will take over the cost in 3 years.	
Pros and cons and reflections	<p>Pros</p> <ul style="list-style-type: none"> • A much-needed level 4 CPC consultant has been appointed • NHS trusts and charities have developed a partnership to meet the needs of the children and families, that they both support. <p>Cons</p> <ul style="list-style-type: none"> • Uncertain what will happen in 3 years if commissioners do not pick up the cost. 	
Network	West Midlands	
Contact details	<p>Name</p> <p>Nicki Fitzmaurice , Deputy Head of Nursing Corporate Nursing, Lead for Palliative and Bereavement Care Services</p>	<p>Email</p> <p>Nicola.fitzmaurice@bch.nhs.uk</p>

Commissioning

Name of the solution	Bespoke advice to localised and specialised commissioning	
Problem it was aiming to solve	Commissioners required somewhere to turn to when they needed expert advice about different aspects of children's palliative care.	
Describe how the solution was implemented	With one network chair linking with the local Clinical Commissioning Groups (CCG) and Sustainability and Transformation Partnerships (STP), the network was able to provide bespoke advice on request to the commissioners, promptly, covering any aspects of children's palliative care, through their network members. A report on children's palliative care was produced for the STP who used it to inform and advise the CCGs	
Pros and cons and reflections	Pros <ul style="list-style-type: none"> • It was effective in the areas that requested the advice as children's palliative care is included now in the STP and CCG plans 	
Network	West Midlands	
Contact details	Name Nicki Fitzmaurice, Deputy Head of Nursing Corporate Nursing, Lead for Palliative and Bereavement Care Services	Email Nicola.fitzmaurice@bch.nhs.uk

Facilities

Name of the solution	Quiet Rooms at Isle of Man and Liverpool airports	
Problem it was aiming to solve	Privacy, comfort and safety for families travelling for treatment and for the bereaved. Families with very sick children travelling e.g. to Liverpool for chemo, were previously having to wait in the main departure lounge, often in crowded situations, increasing the risk of infection and offering no privacy. Similarly, recently bereaved families returning from the mainland, whilst repatriating the body, found it difficult in their distressed stay, to have to wait with holiday makers, in the departure lounge at Liverpool.	
Describe how the solution was implemented	Funding from Breast Cancer Care provided the room, but it is available for people of all ages travelling from Isle of Man to Liverpool for treatments and includes a play area, or from Liverpool when returning after treatment or when repatriating a body after the death on the mainland. The room is comfortable and has a play area. It allows privacy and relaxation.	
Network	North West	
Contact details	Name Katrina McNamara Director of Service Development and Improvement	Email Katrina.mcnamara@togetherforshortlives.org.uk

Facilities

Name of the solution	Magnolia House. A safe haven within a children’s hospital for parents and families, providing a place for children and families living with terminal illnesses or complex diagnosis to process life changing news.	
Problem it was aiming to solve	Lack of space and privacy for families when dealing with distressing news Families needed a quiet space or sanctuary away from the busy wards to allow them the time and space to come to terms with their circumstances.	
Describe how the solution was implemented	The cost was funded by a local organisation, raising the necessary money through fundraising and through public donations. Although space was in very short supply around the hospital grounds, an area was found in a courtyard. The building was purpose built and decorated, with feedback from families Now bad news is no longer delivered in offices or empty cubicles and provides an environment that gives parents the chance to process life changing news.	
Network	West Midlands	
Contact details	Name Nicki Fitzmaurice, Deputy Head of Nursing Corporate Nursing, Lead for Palliative and Bereavement Care Services	Email Nicola.fitzmaurice@bch.nhs.uk

Training

Name of the solution	Regional Education Day	
Problem it was aiming to solve	There was a lack of opportunities for conference attendance, updates, training and exchange of knowledge due to lack of both time and travel expenses, for all grades of HCPs across the region	
Describe how the solution was implemented	The network organises a free annual conference with topical issues covered by local and national presenters. By being free to attend and located centrally within the region, it enables a large number of staff to attend. The topics discussed were national and local but relevant to the region.	
Pros and cons and reflections	<p>Pros</p> <ul style="list-style-type: none"> • it does give everyone the opportunity to be updated on topical local and national issues, and to maintain their knowledge and skills. • It also helps their revalidation <p>Cons</p> <ul style="list-style-type: none"> • Even if all places taken, attendance can be poor when people are pulled back into their clinical role at the last minute due to staff shortages, busy caseloads. 	
Network	West Midlands	
Contact details	<p>Name</p> <p>Nicki Fitzmaurice, Deputy Head of Nursing Corporate Nursing, Lead for Palliative and Bereavement Care Services</p>	<p>Email</p> <p>Nicola.fitzmaurice@bch.nhs.uk</p>

Training

Name of the solution	Satellite education programme for Health Care Professionals (HCP) around the region	
Problem it was aiming to solve	Lack of available training at a local level and lack of opportunity for HCPs to access training elsewhere due to time and cost constraints but also lack of bespoke training availability	
Describe how the solution was implemented	The hospice medical director has developed a Children's Palliative Care education programme which he delivers at the hospitals across the region, on request.	
Pros and cons and reflections	<p>Pros</p> <ul style="list-style-type: none"> • The training is cost effective for the Trusts as several people at once will receive the training. • The training is local, so no travel involved and the time the staff are taken out of the clinical area, is kept to a minimum. <p>Cons</p> <ul style="list-style-type: none"> • Cost of travel for the medical director. • Need to raise awareness of programme 	
Network	West Midlands	
Contact details	Name Mark Hunter, Consultant Paediatrician	Email Mark.hunter@acorns.org.uk

Service Provision

Name of the solution	Identifying gaps across the regional network area	
Problem it was aiming to solve	Meeting the National Institute for Clinical Excellence (NICE) End of Life Care for babies, children and young people guidelines	
Describe how the solution was implemented	All services/organisations within the network were encouraged to undertake the NICE baseline assessment. The information was collated to identify gaps across the network (not just individual services)	
Pros and cons and reflections	<p>Pros</p> <ul style="list-style-type: none"> • The exercise though has helped the network to understand the gaps and to find key areas in which the network can progress together to meet the NICE recommendations <p>Cons</p> <ul style="list-style-type: none"> • It was difficult to get all organisations to engage within the agreed timeframe 	
Network	Thames Valley (South Central)	
Contact details	Name Helen Bennett, Director of Care	Email helenb@alexanderdevine.org

Appendix 1

NICE Guidelines for CPC service data collection questions

	Statement
1	Communication between professionals/parents: Professionals think about how best to communicate with each child or young person and their parents or carers
2	Communication between professionals: services within all relevant agencies engage in planning for the specific needs of the child/young person
3	Information available: Children, young people and their families have easy access to information about their condition and services available to them
4	Advance care plans: Each child or young person and their family has an Advance Care Plan or equivalent
5	Emotional/psychological support is available for children and young people with a life-limiting condition.
6	Religious/spiritual support is available for children and young people with a life-limiting condition.
7	Symptom management: Staff have 24/7 access to specialist advice on complex symptom management in children and young people
8	MDT: Children and young people with life-limiting conditions are cared for by a defined* multi-disciplinary team
9	Family support: Care plans address the care and support needs of all immediate family members
10	Organ and tissue donation: Processes are in place for families to discuss their preferences for organ and tissue donation
11	Recognise likely to die: professionals are able to recognise when a child is likely to die within the next few days
12	EOL care: Every child and family has an end of life plan when appropriate
13	EOL care: Every child approaching the end of life has 24-hour access to paediatric nursing care
14	EOL care: The carers of children approaching the end of life have 24-hour access to advice from a consultant in paediatric palliative care.
15	Rapid transfer: There is a rapid transfer process for children and young people with life-limiting conditions to allow urgent transfer to the preferred place of care
16	Care at home: Every child has access to a 24-hour multi-disciplinary children's palliative care team for care within the home
17	Care after death: the practical arrangements that will be needed after the death of their child are discussed with parents/carers

18	Staff support: Professionals have access to ongoing support and supervision.
19	Bereavement support: Parents or carers are offered bereavement support when their child is nearing the end of their life and after their death.
20	Specialist paediatric palliative care team:
A	Service delivery by a consultant-led multi-professional specialist palliative care team across the network/MCN
B	Clinical leadership role in planning delivery and evaluation of children's palliative care services across a network/ managed clinical network
C	Care led by a medical consultant working at Paediatric Palliative Care Competency Level 4
D	MCN/network provides the full range of specialist paediatric palliative care interventions including use of alternative opioids
E	MCN/network able to treat all children and young people, regardless of their age

Appendix 2

NICE GUIDELINES: LOCAL SOLUTIONS PROFORMA

Name of the solution		
Problem it was aiming to solve		
Describe how the solution was implemented		
Pros and cons and reflections		
Lessons learned		
Contact details	Name	Email