

BMJ Open Quality Chameleon project: a children's end-of-life care quality improvement project

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ABSTRACT

In response to there being no specialist paediatric palliative care (PPC) team in a region of England, we undertook a 12-month quality improvement project (funded by National Health Service England's Marginal Rate Emergency Threshold and Readmission fund) to improve children's end-of-life care. Improvements were implemented during two plan-do-study-act (PDSA) cycles and included specialist experts, clinical champions, focused education and training, and tools and materials to support identification, care planning and communication. A lead paediatrician with expertise in PPC (10 hours/week) led the project, supported by a PPC nurse (3 days/week) and a network administrator (2 days/week). Children who died an expected death were identified from the child death review teams. Numbers of non-elective hospital admissions, bed days, and costs were identified. Twenty-nine children died an expected death during the 12 months of the project and coincidentally 29 children died an expected death during the previous 12 months. The median number of non-elective admissions in the last 12 months of life was reduced from two per child to one. There was a reduction in specialist hospital (14%) and district general hospital (38%) bed days. The percentage of children who died an expected death who had anticipatory care plans rose from 50% to 72%. The results indicate that a network of clinicians with expertise in PPC working together across a region can improve personalised care planning and reduce admissions and bed days for children in their last year-of-life with reduced bed utilisation costs.

PROBLEM

East Midlands north (EM north) has a population of 614631 children (<18 years). There is one specialist children's hospital, plus acute general and community paediatric services based around three district general hospitals (DGHs). There are approximately 4000 children living with life-limiting (LLCs) and life-threatening conditions (LTCs) in EM north¹ and 750 children needing palliative and end-of-life care services each year.² There is no paediatric palliative care (PPC) team in the region's children's hospital and while some hospice services are available, there is no children's hospice situated in EM north. There is some district health

funding for community paediatrician support for children with medical complexity and palliative care needs in one district, but there is no other paediatrician resource specifically identified for palliative or end-of-life care.³

There are three district children's community nursing (CCN) teams who, together with the paediatric oncology outreach nurses from the children's hospital, provide care in the community for children with LLCs. Two of the CCN teams provide out of hours support for end-of-life care in the home on an 'ad hoc' basis. One of the teams is specifically commissioned to provide a 24/7 on call service for children needing end-of-life care at home but is not always adequately staffed to deliver this.

As well as affecting clinical care for children and families, the lack of specialist PPC resource limits service evaluation, development and training to the current work force.

The National Health Service England (NHSE) Marginal Rate Emergency Threshold and Readmission Fund supported a 12-month project to improve the quality and cost efficiency of palliative and end-of-life care for children in EM north.

BACKGROUND

Together for Short Lives, a UK charity supporting children, families and professionals, describes four categories of LLCs and LTCs:

- Conditions where curative treatment is possible but can in some cases fail and lead to death (eg, cancers).
- Conditions whereby an early death is unavoidable and inevitable (eg, cystic fibrosis).
- Progressive conditions with no feasible treatment for cure (eg, neurodegenerative conditions).
- Conditions which are irreversible but non-progressive, which lead to increased risk of other health complications which could lead to death (eg, severe neurodisability leading to increased risk of life-threatening chest infections).⁴



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The prevalence of children in England with LLCs or LTCs increased to 86625 in 2017/2018 compared with 32975 in 2001/2002.¹ These children often have prolonged admissions to neonatal and paediatric intensive care units (PICUs) and may be transferred to specialist surgical units for multiple surgeries in the first years of life. Once home they often remain under the care of specialist teams, have frequent hospital admissions and many die in a critical care unit. This has serious implications for the use of NHS resources, particularly the flow through critical care units, but also for the quality of life of the children and their families.

A national cohort study in 2017 showed that children with LLCs accounted for nearly 58% of admissions to PICUs, 72% of PICU bed days, 87.5% of stays greater than 28 days and 73% of deaths in PICU.⁵

A recent review by NHS England regarding Paediatric Critical Care and Specialised Surgery in Children states that units are under increasing pressure and critical care is not sustainable in its current format. There are significant increases in lengths of stay with 10% of children (mostly with medical complexity and LLCs) using over 50% of resources. The report concludes that some of these children could be moved out of critical care and new models of care need to be explored.⁶ Specialist PPC services working with paediatric critical care and also developing the skills of local district and community teams could enable choice around place of care for these children and families and develop new care pathways. The UK National Institute for Health and Care Excellence (NICE) guidance for end-of-life care for infants, children and young people with LLCs: planning and management⁷ recommends that children and their parents or carers should be involved in developing an advance care plan with their professional team to plan for and receive end-of-life care that is appropriate and in accordance with their wishes. This guidance also recommends the development of Managed Clinical Networks to support the delivery of children's palliative and end-of-life care across a region. This is also recommended in the new UK NHSE specialist palliative care service specification⁸ (currently in draft) which describes regional specialist PPC teams working with core and universal services in a coordinated way that enables accessible support to manage everyday problems, with access to specialist services when needed.

MEASUREMENT

The child death review registers of EM north were used to identify children (<18 years) who died expected deaths during the project and in the 24 months before the project. Data on place of death, admissions, bed days and admission costs in the last 12 months of life for each child were obtained from hospital records and Healthcare Resource Group data.

The percentage of children with family-held anticipatory care plans prior to their death was ascertained from child death review team data and the child's medical records.

A bereaved family feedback tool was adapted from a Maternity Bereavement Experience measure already in use in the London Neonatal Network. A copy was placed in the child bereavement pack which is given to every family when their child dies.

A staff survey was distributed face to face and by email at 6 and 12 months.

Feedback from the project team was gathered formally and informally at regular intervals.

Individual case studies were used to identify successes and issues.

Templates for prospective data collection and retrospective case note audit of end-of-life care according to NICE quality standards were developed and set up as a Microsoft Access (Microsoft, 2013) database.

Baseline measurement

In 2013, a retrospective case note review showed that only 47% of 53 children with LLCs who died an expected death under the care of the regional children's hospital had anticipatory care planning documentation and only one child was transferred from hospital to hospice for end-of-life care. It was concluded that the majority of end-of-life planning occurred close to the time of death and was documented within the narrative of the medical records rather than on the recommended family-held templates. It was recommended that planning should begin earlier when death could be considered a significant possibility rather than a certainty.⁹

DESIGN

The proposal was for a specialist PCC team based in the children's hospital plus additional resource for a paediatrician with expertise in each of the three DGH areas to provide:

- ▶ Development and dissemination of pathways, templates and prompts to support personalised care planning (PCP) with children with LLCs and their families.
- ▶ Specialist paediatrician and PCC nurse support, including attendance at ward rounds and joint clinics.
- ▶ Education and training regarding PCC and end-of-life care to clinical teams.
- ▶ Development of clinical champions within key teams to work together as a coordinated children's end-of-life care network.
- ▶ Development of regional data collection systems and data sets for service audit.

A series of interventions were planned that involved the provision of direct clinical care, consultation, leadership, service development and evaluation of end-of-life care for children across EM north. Specifically, this translated into three broad interventions: Specialist Paediatricians and Nurse Specialist, education and training programmes, and clinical champions.

Rationale for these interventions

Specialist paediatricians and nurse specialist

The UK NICE guidance⁷ recommends that the care team includes members of a specialist PPC team which should

Flags to help identification

Diagnosis of a condition which is highly likely to be lethal in a short time frame

Lack of response to treatment

Frequency of admissions with life threatening events is high or increasing

Rapid progression of disease

Multi organ failure

Agreed consensus that the child's quality of life is so poor that further invasive treatments are no longer appropriate

Cachexia despite nutritional support

Contact details

Once you have identified a child for the project please inform the team of the child's name, date of birth and NHS / hospital number preferably by email.



Prompt for consideration of parallel planning around End of Life Care

Would you be **surprised** to hear this child had died and/or is there a **possibility** this child may die within the next:

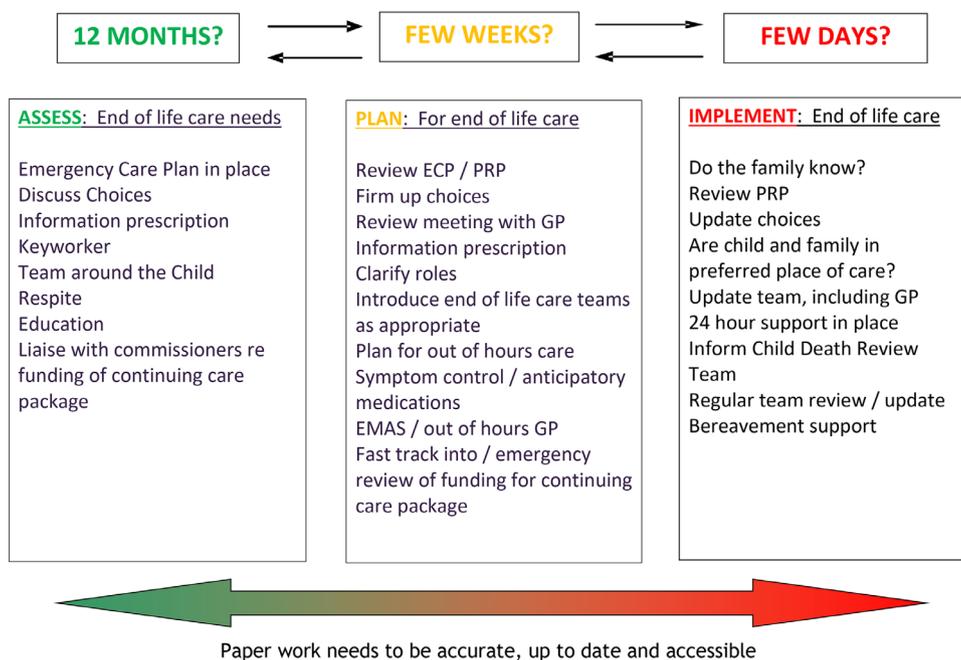


Figure 1 Prompt Tool for Children's End of Life Care Planning.

consist of a minimum of a PPC consultant and a nurse with expertise in PPC. Furthermore, the implementation of nurse specialists in palliative care based within a hospital has been recognised as an asset for ward-based staff to improve their delivery of palliative care.^{10 11}

Education and training

There are several studies making a strong case for the significant impact that formal palliative care training can have on clinical staff care delivery when palliative care is integrated into their clinical patient care work¹²⁻¹⁴ and a variety of educational approaches have been referred to in the literature, including on-site sessions and distance learning,¹⁵ study half days,¹⁶ simulation study days^{17 18} and ongoing training programmes.^{19 20}

Clinical Champions

Studies have evaluated the effect of a network of ward-based nurse champions or link nurses acting as intermediates between palliative care experts and general ward staff. The position of a nurse champion can be both a role model and a source of reference for staff²¹ and a network of palliative care nurse champions can affect care by education, knowledge dissemination and support.²²

The project team

Medical sessions for the specialist PPC paediatrician role were allocated to paediatricians already working in the children's hospital who had some expertise in palliative care with the aim of embedding learning from the project to other paediatricians and their clinical teams.

The project team consisted of a project lead paediatrician (TW), who was a neurodisability paediatrician (10 hours per week), a project nurse who was a specialist PPC nurse (CD) (3 days per week), and a network administrator/data clerk (ACo) (2 days per week). Paediatrician champions in the intensive care unit (PICU) (NK), oncology (JT) and neonatal intensive care unit (NICU) (AD), were funded 2 hours per week each, and a neurodisability paediatrician in each of the three districts of the region (HC, HG, ACh) was funded 4 hours per week to lead on the project in their locality.

Supporting resources were supplied to each team member including copies of a PPC handbook,²³ online guidelines from Together for short lives,²⁴ and the Association of Paediatric Palliative Medicine.²⁵

Service level agreements were developed to support working together across conventional organisational and geographical boundaries. The project was registered with the audit department of each contributing organisation. There were monthly project team meetings, with the project team engaging the senior management team by reporting every 2 months to the children's hospital Innovation and Safety Committee.

Leaflets about the project and how to contact the team were developed together with the Prompt tool (figure 1). PCP tools in paper and online formats were developed and agreed with clinicians across the region including the Emergency healthcare and Resuscitation Plan template and the Chameleon Choices document (see online supplemental materials 3 and 4).

STRATEGY

During the first 3 months, the project team was recruited, and project materials were developed and distributed to all paediatric clinical areas. Awareness raising sessions were held and the teaching programme was developed.

PDSA CYCLE 1

Plan

The strategy was to encourage clinical teams within the children's hospital and district paediatric services to identify children likely to be in the last 12 months of life and to use the project materials with project team support to undertake timely PCPs, and link with community and hospice services.

Do

Members of the project team attended ward rounds on the oncology unit (JT), NICU and PICU (CD) on a weekly basis and also worked with the CCN teams (CD, TW) to identify children likely to be in the last 12 months of life. The project paediatrician champions (JT, NK, AD, HG, HC and ACh) took the lead within their departments for promoting the project materials, identifying of, and referring children to the project. End-of-life care champions were identified on each of the wards.

Standardised PCP tools were embedded into each participating organisation, as well as regional neuromuscular and long-term ventilation services, via the local project champions (HG, HC and ACh) and the project team (CD and TW) which supported referring clinicians to undertake PCP. The materials included details of community and hospice services.

The project lead paediatrician (TW) provided monthly palliative care clinics for care planning and symptom management jointly with two (HG and ACh) of the project DGH paediatricians. In the third locality the project lead paediatrician provided telephone and face to face consultations with the project DGH paediatrician (HC), and a monthly peer review meeting was established which later included the other project DGH paediatricians.

Formal half day teaching sessions were provided in each locality (CD, TW and NK).

STUDY AT 6 MONTHS AND ACTIONS

A retrospective case notes audit of children's end-of-life care using NICE quality standards showed improvement in PCP.

End-of-life care champions who had been identified on each ward in the children's hospital were merely acting as a project link and sign-posting to the project materials. Protected time for them to meet as a group for PPC training and mutual support was therefore arranged via senior nurse managers.

A survey of children's hospital staff and community nurses showed that clinicians who had worked with the project team were very positive about its impact. Senior nurse managers were aware of the project but many 'patient facing' nurses had not heard of it. The project nurse became more proactive in reaching out to patient facing nurses. She started checking the children's hospital NerveCentre electronic patient system daily and the 'long stayers' report weekly for children on the wards who had a long-term condition or a resuscitation plan. She then looked at the PCP documentation with the child's named nurse, supporting them to become involved in the care planning process.

Several children with LLCs and LTCs had been identified on the surgical and neurology wards. Presentations of case studies and family feedback were made to the surgeons and the project nurse started to attend the paediatric neurology ward rounds weekly.

The transfer of children out of PICU for end-of-life care had raised issues about the use of syringe drivers to deliver subcutaneous infusions. Guidelines were therefore developed and shared across organisations.

There had been few referrals to the project from the neonatologists. They fed back that there was often too much uncertainty or too short a time to offer options for transferring care out of NICU at end-of-life. The project team met with the foetal medicine team to develop the pathway for earlier joint working and parallel planning for babies identified with potentially LLCs in utero.

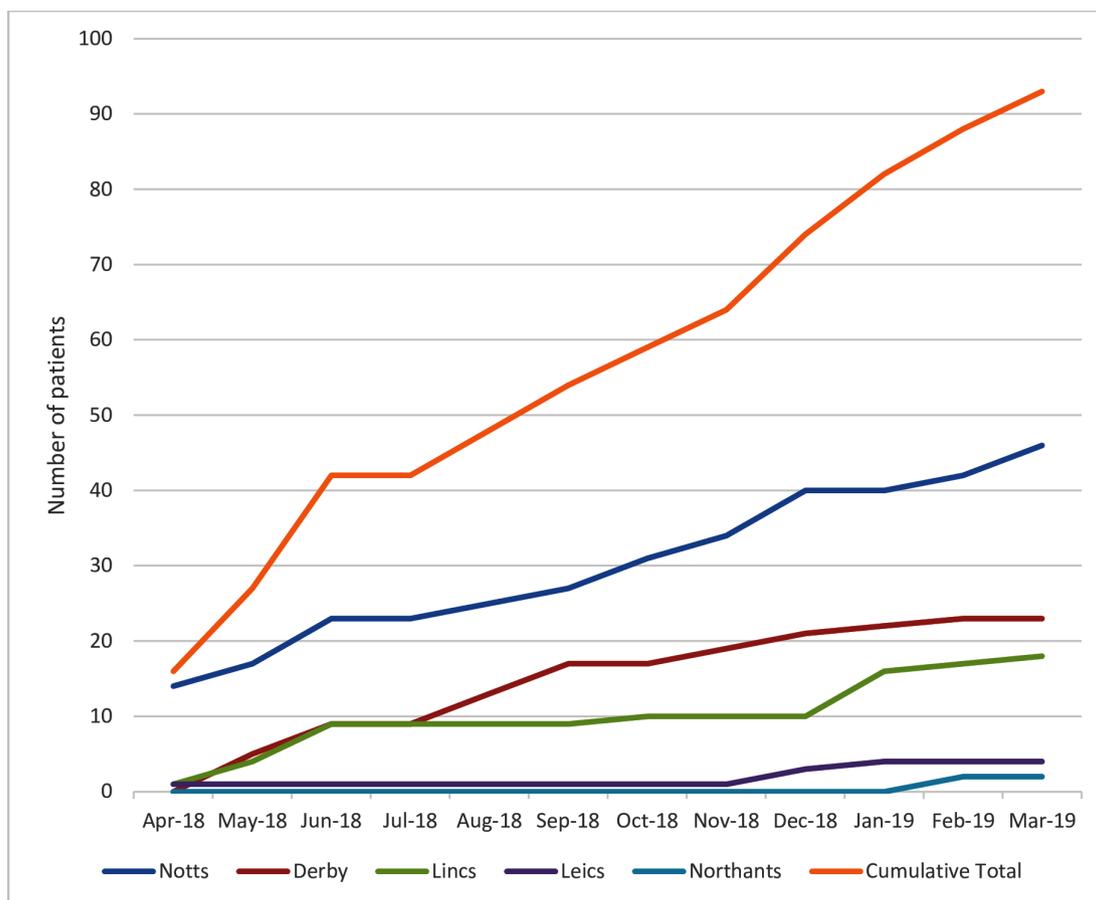


Figure 2 Cumulative data on patients identified to the Chameleon team by geographical region.

PDSA CYCLE 2

The project had become embedded in PICU. The project nurse was now chairing multidisciplinary team meetings to support the development of consensus across the specialty teams involved with children with medical complexity.

An ‘introduction to PPC’ session was developed, which became embedded in the new starter programme for nurses across the children’s hospital and part of role-related training. The team ran a training day for trainee paediatricians which evaluated very well and were allocated a regular session on the teaching programme.

Neonatal bereavement nurses were appointed and had training from the project team to enable them to support end-of-life care planning on NICU.

The long-term ventilation nurses, therapists and the muscular dystrophy family support worker were supported to enter the child’s respiratory escalation plans on to the PCP template, start choices discussions with the child and family and then they supported the respiratory and neurology paediatricians to complete and sign the plans with the parents or young person themselves in clinic.

A further survey of children’s hospital staff was undertaken at 12 months. Data on place of death, admissions, bed days and admission costs in the last 12 months of life for each child who had died an expected death during

the project and during the 24 months prior to the project were collected and compared.

RESULTS

At 12 months, 101 children had been identified to the project (figure 2) and 70% of them had PCPs completed. A total of 24 questionnaires were completed by children’s hospital staff. Twenty-three staff (96%) had heard of the project, and 14 (58%) had worked with the project team. The project materials and teaching sessions were rated positively, but it was the direct contact with the project nurse and her support with individual case management that was most highly appreciated. The prospect of dealing with end-of-life care was reported as a difficult area for most clinicians to manage. Many respondents related a sense of relief to have support for early planning and decision making with families. Several clinicians said they had some experience but not enough specialist knowledge or time to do PCP well without support. ‘She has time and knowledge to give families information and emotional support which we don’t’. ‘...given me the confidence to approach difficult conversations with families’ ‘...given me the confidence to challenge the medical plan’.

Feedback from members of the project team identified the face to face and telephone support from the project nurse and lead paediatrician as the most useful, followed

Table 1 Non-elective admissions and bed days in last 12 months of life for children and young people (non neonates) who died an expected death, identified from child death review teams of East Midlands North—Nottinghamshire, Derbyshire and Lincolnshire

| Financial year | 2016–2017 (12 months) | 2017–2018 (12 months) | 2018–2019 (12 months) |
|--------------------------------------|-----------------------|-----------------------|-----------------------|
| No of expected child deaths | 24 | 29 | 29 |
| Total admissions | 94 | 78 | 56 |
| Max per child | 23 | 6 | 10 |
| Median (IQR) | 2 (1–4) | 2 (1–4) | 1 (1–2) |
| Total bed days | 717 | 1054 | 855 |
| Max per child | 107 | 198 | 251 |
| Median (IQR) | 16 (2–55) | 15 (5–58) | 12 (1–31) |
| District hospital admissions | 52 | 29 | 19 |
| Max per child | 23 | 6 | 6 |
| District hospital bed days | 152 | 201 | 124 |
| Max per child | 45 | 76 | 91 |
| Specialist hospital admissions | 42 | 49 | 37 |
| Max per child | 7 | 6 | 10 |
| Median (IQR) | 1 (0–3) | 1 (0–3) | 1 (0–2) |
| Specialist hospital bed days | 565 | 853 | 731 |
| Max per child | 82 | 198 | 251 |
| Median (IQR) | 8 (0–55) | 8 (0–35) | 8 (0–26) |
| Specialist hospital admissions costs | £751 956* | £1 140 911 | £830 222 |
| Max per child | | £371 599 | £167 121 |
| Median | | £13 037 | £12 596 |
| (IQR) | | (0–£25, 845) | (0–£43,394) |

*Financial data imputed due to incomplete data and costing changes.

by the PCP materials. All clinicians in the project team expressed how time consuming the work was and the need for more time in their job plans. The paediatricians in the project team reported problems due to lack of CCN support for 24/7 care and that they themselves were supporting children to die at home including telephone support and home visits out of normal working hours.

Formal teaching sessions on PCP, symptom management and ethical dilemmas were delivered over the 12 months of the project to 47 paediatricians, 85 nurses and 9 others.²⁶

As outlined in table 1, 29 children died an expected death during the project year and coincidentally 29 children died an expected death in the 12 months before the project. The median number of hospital admissions of children in the last 12 months of life went down from two per child, to one per child. The total number of admissions decreased from a total of 78 admissions, for the 29 children who died in the year before the project, to 56, for the 29 children who died during the project (28% reduction). Furthermore, specialist bed days were reduced from 853 to 731 (14% reduction) and DGH bed days were reduced from 201 to 124 (38% reduction).

The costs of the children's hospital specialist and critical care bed utilisation for 29 children in the last 12 months of life was reduced from £1 104 774 in the year before the project to £830 222 in the project year. However, it should

be noted that the total number of bed days and costs were heavily impacted by a small number of children.

As shown in online supplemental table 2, 10 children died from oncology conditions during the project year and the same number in the previous year. The median number of hospital admissions in the last 12 months of life for these children went down from four to one and median oncology ward bed days went down from 19 days to 9 days. Documentation of PCP on NICU improved during the project, but there had been no reduction in length of stay.²⁶

The audit of the medical records of children who died an expected death in East Midlands north between April 2017 and December 2018 showed that the percentage of children who had documented PCPs rose from 50% to 72%. However, the availability of 24/7 community nursing support when place of death was home fell from 100% to 50%. The percentage of children dying outside hospital was unchanged during the project. More children died in a hospice but fewer at home.

The bereaved family anonymous feedback tool had been given to 20 families in the bereavement pack. The response rate was low, with only 4 out of 20 surveys returned. All respondents said they felt supported in the time leading up to their child's death, and that professionals communicated with them in a sensitive way. 3/4 said that they were fully involved in decisions about their

child's care, had choices around where that could be, that they had a written plan for their child's care and treatment in an emergency and at end-of-life.

Case studies in online supplemental table 3 illustrated the role of the project team in promoting earlier PCP and supporting end of life care out of hospital with resultant hospital bed utilisation cost savings.

Lessons and limitations

Several of the specialist clinical teams in the children's hospital were initially wary that the project team would take over the care of the patient or disrupt their delicate relationship with the child and family. Despite wide dissemination of the project leaflets and presentations it took time and experience for paediatricians to understand how the project could help them and to develop trust in the team.

Palliative care was generally perceived as something to be introduced only when treatment interventions had failed. More emphasis on parallel planning²⁷ in our initial project information would have been useful to encourage clinicians to seek advice from the project team early rather than waiting until it was clear that the child was dying.

The PCP materials were widely shared and embedded. The formal teaching provided was highly rated in relevance and content. No specific tests of improved knowledge were undertaken, however, staff surveys showed improved confidence and satisfaction in providing end-of-life care and our data suggests that there has been a change in practice as PCP improved and hospital bed days were reduced. Several clinicians fed back that they continued to value the practical support from the project nurse for difficult conversations and symptom management at the bedside for individual cases as they arose. Having consultant paediatrician champions within key teams who had some funded time for the project in their job plans helped with paediatrician engagement and change in practice. They had knowledge and expertise of their specialty and also the respect of their team. They were able to endorse the project and set an example of how to work with it.

Having several doctors engaged with the project provided mutual support and more medical cover across the week. Monthly project team meetings and a professionals' shared area on the intranet helped share documents and teaching materials within the children's hospital. The service level agreements supported the sharing of data across organisations. Clinicians found the collection of data too time consuming and the role of the network administrator/data analyst was essential for data collation.

All clinicians involved with the project stated that it was very time-consuming work. PCP for a child with a neurodegenerative condition in an outpatient setting may take many hours of paediatrician and nurse time over several weeks, whereas for a child who is deteriorating on PICU, this may need to be accomplished in 1 day, particularly if the family want to transfer elsewhere for end-of-life care.

The PICU team did not always have the capacity to do this when the unit was busy and the availability of the project nurse to support or do much of this was highly appreciated.

Case studies and patient journeys demonstrated that it was a coordinated network of clinicians working together across organisational boundaries that provided the combination of specialist expertise and local support to improve care planning, and choices for families.

The role of the specialist PPC nurse (the project nurse) was central to the success of the project. She provided much of the teaching programme and the bedside support for all professionals in the children's hospital. There was very positive feedback from staff about her role. There was a lack of formal user feedback due to the low responder rate to the anonymous bereaved parent feedback questionnaire. The response rate may be improved by clinicians giving the tool to the parents in a face-to-face meeting after a child has died. The project team had very positive feedback from the parents they were supporting during the project, and this was captured in case studies. It would have been useful to ask for anonymous child and parent feedback at various stages during the patient's journey.

CONCLUSION

The project provided a team of clinicians with expertise in children's end-of-life care who worked together to embed a system of earlier identification and PCP across a region. Hospital admissions, bed days and costs for children in the last 12 months of life were reduced and advance care planning increased. Staff reported increased confidence and satisfaction when providing end-of-life care. Having paediatricians with expertise in PPC in each DGH working together with the specialist PPC team in the tertiary children's hospital, can support coordination and quality improvement of services for children with palliative and end-of-life care needs across a regional network with improved care and choice for children and families.

The lack of resilient community nursing teams with the ability to reliably provide a 24/7 face-to-face on call service for children's end-of-life care at home reduces patient choice at end-of-life.

Sustainability

The project materials including the end-of-life care prompt and the PCP templates remain embedded in the organisations across the region and awareness and expectations of the paediatric workforce have been raised.

Subsequent to the project the three integrated care systems (ICSs) of the region have jointly invested in a children's palliative care network coordinator role to continue the quality improvement process. Two of the ICSs have provided on-going funding for paediatricians with expertise in PPC in their local DGHs. The children's hospital has invested in a substantive PPC nurse post, and the paediatrician end-of-life care champions in the

children's hospital continue to provide the role despite no further funding. The data from the project has supported a business case for a consultant in PPC for the region.

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Table 2: Non elective admissions and bed days in last 12 months of life for children (non neonates) with oncology conditions - EM north

| | 2016 | 2017 | 2018 |
|---|-----------|-----------|----------|
| Children with oncology conditions who died | 12 | 10 | 10 |
| Emergency department attendances | 13 | 11 | 8 |
| Number of hospital admissions in last 12 months of life | 74 | 64 | 23 |
| Median (IQR) | 3 (2-9) | 4 (3-5) | 1 (0-2) |
| Oncology ward bed days | 346 | 279 | 112 |
| Median (IQR) | 25 (3-57) | 19 (8-50) | 9 (0-18) |
| District hospital ward bed days | 88 | 69 | 11 |
| Paediatric critical care bed days | 87 | 30 | 37 |
| | | | |

Table 3: Chameleon Illustrative Case Studies

| Setting | Before Chameleon Project | During Chameleon Project |
|----------------------|---|--|
| PICU | <p>Female infant, born 2 months preterm with a major congenital abnormality which at first seemed amenable to surgical correction. She had two surgical repairs but remained ventilator dependent and developed chronic lung disease.</p> <p>She was ventilated for 3 months on the neonatal intensive care unit and then was transferred to the paediatric intensive care unit where she was ventilated for another 4 months. She had life threatening complications and despite continuing intensive care she deteriorated and died at 7 months of age on PICU.</p> | <p>Male infant, born 2 months preterm in 2018 with a major congenital abnormality. The surgeons were initially hopeful that this could be corrected if he could be kept alive and if he could grow bigger. He was ventilated on the neonatal intensive care unit for three months and then transferred to the paediatric intensive care unit.</p> <p>He was having recurrent life-threatening deteriorations and discussions with parents regarding personalised care planning and parallel planning were led by the Chameleon team. After 2 weeks his parents and the medical team agreed that it was in his best interests to stop the ventilation and he died on the unit at 4 months of age.</p> |
| PICU Bed days | 134 | 17 |
| Actual Costs | £238,536 | £30,567 |
| Oncology | A 6-year-old male was diagnosed with a diffuse brain tumour, of a type that is universally fatal. The tumour progressed on treatment. He was admitted for investigations and supportive care for his deterioration | A 5-year-old female was diagnosed with diffuse brain tumour. Her oncologist held early discussions with the family about the nature of her illness and that this was incurable. |

| | | |
|--|--|--|
| | <p>and his parents then did not want to leave the hospital. There were a number of attempts to introduce the idea of hospice or home care, but they did not want this. Partly this stemmed from not being able to accept that his disease was not treatable.</p> <p>The child deteriorated to the extent that he lost all ability to communicate, eat and drink and was lying passively in bed, with fluid and nutrition via nasogastric tube. His parents were reluctant to stop this as they felt he may suffer. A number of tests and opinions were sought to assess what brain function remained. Hospice and home were introduced again but declined. He had a long inpatient stay on the oncology ward in the children's hospital for 4 months.</p> <p>After death, he and his family were transferred to the cold room at the hospice. Parents expressed regret at not having been to the hospice before he died.</p> | <p>As her diagnosis was known to be life-limiting she was highlighted to the Chameleon team. When she had a deterioration the Chameleon champion oncologist was able to have end of life care discussions with the family including the benefits of hospice care. A personalised care and resuscitation plan was documented with the help of the Chameleon team, who also helped to arrange her transfer to the hospice within 48 hours of her emergency admission. Her symptoms were brought under better control, and she remained at the hospice, with some days at home, until her death 4 months later.</p> <p>She had many good experiences during her last months, including swimming in the hospice pool and regular visits to the garden. The environment was also much better for her family to visit. Because of the advanced care planning it was possible to make arrangements for research donation of her organs, which was some comfort to the family.</p> |
|--|--|--|

| | | |
|------------|--|---|
| DGH | <p>A male infant was born with multiple congenital abnormalities including a severe congenital cardiac defect which was confirmed to be inoperable shortly after birth. The baby spent 13 days on the neonatal unit of the DGH where he was assessed by several different teams. The parents were told that his prognosis was likely death in the first 12 months of life and he went home with a follow up appointment in the general paediatric clinic and support from the community nurses for nasogastric tube feeding. Referral to the hospice was offered but the parents felt it was too far away from home. The community nursing team were not able to offer face to face support for end of life care at home outside normal working hours, but did provide regular home visits for practical and emotional support. He was admitted to the general paediatric ward six times for a total of 76 days before he died as an inpatient at seven months of age. Post death care was provided by the community nurses.</p> | <p>Female infant was found to have a lethal congenital abnormality antenatally. Her parents were counselled about the poor prognosis and that she was most likely to die at the time of birth or soon after. She breathed at birth and was nursed in the birthing unit overnight with expectations that she would not survive, however she remained stable and the Chameleon team were asked to support her paediatrician to discuss discharge home and ongoing palliative / end of life care.</p> <p>The project DGH paediatrician met with parents to make the resuscitation plan, organise end of life support and prescribe medication (morphine and midazolam) to take home. She liaised with the local community nursing team who were unable to provide face to face home support over the weekend. The hospice team were contacted by the project DGH paediatrician and they provided outreach support to the home and support with memory making.</p> <p>The project DGH paediatrician worked with the children's community nurse to provide nursing and paediatrician home visits during the next weeks. Advice</p> |
|------------|--|---|

| | | |
|------------------------|---|---|
| | | <p>was provided by the project lead paediatrician regarding anticipatory symptom management plans.</p> <p>The baby deteriorated at home and the choice of place of death was revisited. Her parents wished to stay at home with telephone support from the project DGH paediatrician and the community nurse. No face to face children's community nursing service was available outside normal working hours. When she was dying her parents chose to bring her in to the ward where the project DGH paediatrician provided the medical care. Her parents remained with her after death overnight in the parents' suite, using a cool cot obtained from the maternity unit. Post death care was provided by the community nurse.</p> |
| NICU bed days | 13 | 0 |
| DGH bed days | 76 | 1 |
| Estimated costs | £ 44,960 £1,120 /day on NICU £30,400 £400 /day on ward £14,560 | £400 |



Choices

This document helps the child's medical and nursing team to explore and record the child and family wishes and choices for care of a child with a life limiting or life threatening condition in the event of significant deterioration

| | |
|--|---|
| <p><u>Child Profile</u></p> <p>Name of Child:</p> <p>Preferred Name:</p> <p>Male/female:</p> <p>Address:</p> | <p>Date Of Birth:</p> <p>Hospital Number:</p> <p>Ethnicity:</p> <p>Spoken Language:</p> <p>Religion:</p> |
| <p><u>Family profile</u></p> <p>Mother's Name:</p> <p>Spoken Language:</p> <p>Is interpreter required: Yes/No</p> <p>Mother's Address / Telephone number:</p> | <p>Father's name:</p> <p>Spoken Language:</p> <p>Is interpreter required: Yes/No</p> <p>Father's Address / Telephone number</p> |
| <p>Are Parents: Married /Partners/ Single/Divorced/Separated</p> <p><i>(If living separately: Ensure both addresses for contacting parents are recorded)</i></p> <p>Child lives with:</p> <p>Person with legal responsibility for the child:</p> <p>Names and ages of siblings:</p> <p>Significant others e.g. Grandparents, Foster carers:</p> | |



| Role | Name | Contact Details |
|---------------------------------------|-------------|------------------------|
| Named medical lead | | |
| Named non-medical lead (Keyworker) | | |

Significant People – Family/Friends/Professionals/Carers

| Name | Relationship | Contact details |
|-------------|---|------------------------|
| | | |
| | | |
| | | |
| | GP | |
| | Children's Community Nurse | |
| | Children's Hospice | |
| | Specialist Social worker | |
| | Family Support worker | |
| | Psychologist | |
| | Physiotherapist /Occupational | |



| | Therapist | |
|-------------|---|------------------------|
| Name | Relationship | Contact details |
| | Charity/voluntary Organisation | |
| | | |
| | | |
| | | |

| | |
|--|---------------|
| Is an Emergency Care Plan/Personal Resuscitation Plan in place? | Yes/No |
| Has 'out of hours' Emergency GP been notified? | Yes/No |

**Family's Level of Understanding and Emotional Support Needs:**

Please give consideration to the family's emotional needs and how they are coping with the situation they find themselves in.

Please consider the support systems that the child and their family have in place and whether further referrals are required. Get child / family permission before sharing any information.

Agencies that may be able to help include:

Child Bereavement Team
Butterfly Project
Local Hospice
Specialist Social Worker
Specialist Nurse
Psychology team
Counselling services
Child/young person's school
Support organisation for child's specific condition
Child Bereavement Trust
Winston's Wish charity

There are many useful leaflets and workbooks available to help families.

Resources are available to assist in the completion of this document. These should be made available to professionals and families. All information has been chosen for being informative and accessible for professionals and families.



| What is the child's understanding of their situation | | Sign | Date |
|--|--|-------------|-------------|
| Discussion held with | | | |
| Give details of understanding wishes during life | | | |
| Action taken | | | |
| What do the parents understand about their child's situation? | | Sign | Date |
| Discussion held with | | | |
| Give details of understanding, beliefs, wishes during life | | | |
| Action taken | | | |



| | | | |
|--|--|-------------|-------------|
| What do the sibling's understand about the situation? Please be aware each sibling knowledge and understanding may be different and should therefore be documented separately. | | Sign | Date |
| Discussion held with | | | |
| Give details of understanding, beliefs, wishes during life | | | |
| Action taken | | | |

| | | | |
|---|--|-------------|-------------|
| What do extended family/support network understand about the situation? What are their support needs? | | Sign | Date |
| Discussion with | | | |
| Give details of understanding, beliefs, wishes during life | | | |
| Action taken | | | |



| | | | |
|--|--|-------------|-------------|
| <p><u>Practical and support needs</u> - <i>If relevant to the choices they can make</i></p> <p>E.g. Housing, financial, employment, respite care, educational, play, complementary therapy or transport needs/issues etc?</p> | | Sign | Date |
| Discussion with | | | |
| Action taken | | | |

| | | | |
|---|----------------|-------------|-------------|
| <p><u>Keepsakes and memory activities</u></p> <p>Have the family been offered the opportunity to obtain keepsakes whilst the child is well and still able to contribute themselves.</p> <p>The family may wish to consider compiling life/memory books/diaries/video diaries, as well as taking hand and foot prints, jewellery, castings, clay imprints.</p> <p>The family may also like keepsakes of all family members.</p> | | | |
| | Details | Sign | Date |
| Discussion with | | | |
| Action taken | | | |



Specific choices around the time of death

It is important to take the child's wishes into account where possible.

Circumstances and events around the child's condition and death may cause these choices to change, so these should be revisited as often as necessary, according to child and family's needs.

| | Name | Contact Details |
|---|------|-----------------|
| Keyworker for pre and post bereavement Support | | |

Where would the family prefer their child's death to take place, if choice is a possibility at the time?

HOME

HOSPICE

HOSPITAL

OTHER;

| | Details | Sign | Date |
|--------------------------------|---------|------|------|
| Discussion with | | | |
| Child and Family wishes | | | |
| Actions Taken | | | |



| | |
|---|------------------|
| If at home, who will certify death? | |
| Name: | Contact Details: |
| | |
| Who would the family like to be with them at the time of death? (Immediate family, extended family, community nurse, specialist nurse, support worker, GP, religious/cultural representative - <i>it is not always possible for professionals to be present</i>) | |
| Names: | Contact Details |
| | |

| | | | |
|--|----------------|-------------|-------------|
| Are these any specific Cultural/Religious or Spiritual needs that need to be considered/ performed during last few days of life? E.g. Would they like their child to be blessed / baptised, does the child need to be facing a certain direction, ambient lighting, and music? | | | |
| | Details | Sign | Date |
| Discussion with | | | |
| Discussion of families wishes | | | |
| Action taken | | | |



Tissue Donation

Before & following a death some families may wish to consider donating organs or tissue for the purposes of transplantation or research. If this is requested by the family then the key worker should contact the On-call Donor co-ordinator (via Switchboard).

They will then give the family all the advice and information to help them reach an informed decision.

Corneas can be obtained up to 24 hours after death
Heart valves can be obtained up to 48 hours after death.

Unless the child is attached to a ventilator on PICU, it would not be possible to donate any organs for transplantation, although donation for research purposes may be possible.

Because of the short time frame whenever possible it is helpful to have explored this choice beforehand. Detailed information is best given on a family by family basis.

| | Details | Sign | Date |
|------------------------|----------------|-------------|-------------|
| Discussion with | | | |
| Family's choice | | | |
| Action Taken | | | |



| | | | | |
|--|----------------|---------------|--------------|----|
| Would the family like help with planning the funeral before or after death? | | Yes Before | Yes After | No |
| Do they wish to speak to a funeral director or religious support? | | | Yes | No |
| | Details | Sign | Date | |
| Discussion with | | | | |
| Child and Family's wishes | | | | |
| Action taken | | | | |
| <p>Details of Funeral Directors – if already chosen by family</p> <p>Name:</p> <p>Contact details:</p> <p>Have the family decided on burial or cremation <input type="checkbox"/></p> | | | | |



| Are there any specific Cultural/Religious or cultural need that need to be considered after death? | | Sign | Date |
|---|--|-------------|-------------|
| Discussion with | | | |
| Details | | | |
| Action Taken | | | |

| Care of child after death - Family should be made aware of the choices for care of their child after death (Keep the child at home, collection by funeral director, hospice, embalmed and returned home, cultural or religious observances etc.) | | Sign | Date |
|--|--|-------------|-------------|
| Discussion with | | | |
| Family's wishes | | | |
| Action taken | | | |



Child Death Review Process

Parents and family members should be informed that their child's death will be reviewed anonymously through the Child Death Review process. This is to ensure that any lessons are learnt; improvements to services are made and appropriate support is provided for the family.

Parents should be informed on how they can contribute their views to the process.

The differences and implication for families regarding expected and unexpected deaths should be explained.

Parents should be provided with literature that explains the review process.

Please contact the Child Death Review Team for any further information

Parents informed on:.....

Post Mortem Examinations

Some families may express an interest in having a post mortem after the death of their child.

This may help answer questions and may help with the planning of any future pregnancies etc.

In this situation please contact the pathology team.

| | Details | Sign | Date |
|-----------------|----------------|-------------|-------------|
| Discussion with | | | |
| Families choice | | | |

| | | |
|---|-------------------|--|
| What arrangements would the family like for collection of equipment/drugs from for the home? | Immediately | |
| | After the funeral | |
| | Not sure | |



| Please document where copies of this document are held: | Tick |
|---|------|
| With child or young person with PRP | |
| Family held records | |
| Key worker | |
| Hospital Case Notes | |
| | |
| GP | |
| Community Nurses | |
| Hospice | |
| Other: | |
| Other: | |

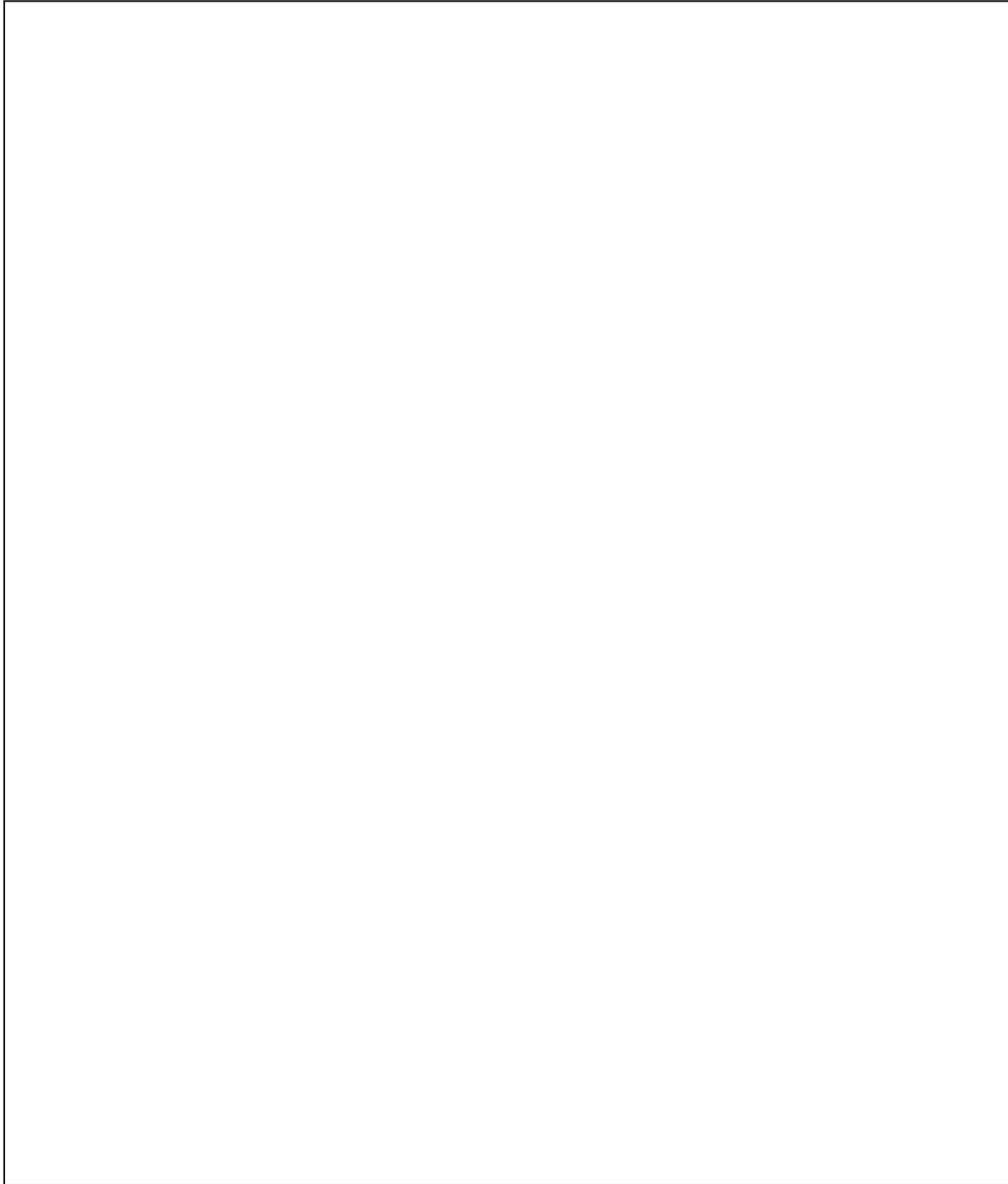
| | |
|-----------------------------|--------------|
| Signed: | Date: |
| Print name and designation: | |
| Contact details : | |

If you would like any assistance in completing this form then please do not hesitate to contact the Child Bereavement Team or the Butterfly Team of specialist family support workers.



Any additional information or choices can be recorded here
(continue overleaf if necessary):

A large, empty rectangular box with a black border, intended for recording additional information or choices. The box is currently blank.



PLEASE KEEP VISIBLE AT THE FRONT OF MEDICAL RECORDS AT ALL TIMES
DO NOT PHOTOCOPY

| |
|----------------------|
| INSERT PATIENT LABEL |
|----------------------|

| |
|-------------------|
| Organisation logo |
|-------------------|

PERSONAL EMERGENCY CARE & RESUSCITATION PLAN FOR

NAME:

NHS NUMBER:

DATE OF BIRTH:

CONSULTANT/G.P:

24 hour contact number for any queries regarding this plan

| | |
|----------------------------|--|
| Date Original Plan Created | |
| Date Current Plan Created | |
| Date Plan no longer needed | |

This Plan does not time expire. It is reviewed regularly as the child/young person's condition changes.

The patient or parent / guardian can change their mind about any of the options contained within this medical care plan at any time.

**PLEASE KEEP WITH CHILD AT ALL TIMES AND AT THE
FRONT OF MEDICAL RECORDS**

DO NOT PHOTOCOPY

PLEASE KEEP VISIBLE AT THE FRONT OF MEDICAL RECORDS AT ALL TIMES
DO NOT PHOTOCOPY

Name
NHS number
Dob
Address
Post code

1. **Background**

Diagnosis/reason for the plan

2. **Resuscitation Plan**

In the event of respiratory and or cardiac arrest:

Symptoms/signs to expect

Select options needed: (Delete options not required)

1. Comfort & support child and family.
2. Reposition to **open the airway** and clear secretions (with suction if available).
3. Give/increase oxygen for comfort via face mask/nasal cannulae.
4. Continue airway management including oral/nasopharyngeal airway if it helps.
5. If still not breathing adequately, give a **trial of five inflation breaths** by mouth to mouth / bag & mask ventilation.
6. Continue mouth to mouth / bag and mask ventilation whilst heart beat present/or until medical assessment.
7. **More invasive resuscitation is not appropriate.**
8. External cardiac compressions / defibrillation / adrenaline should be given.
9. Endotracheal tube & ventilate.
10. Advanced life support including inotropic drugs and iv access.

**PLEASE KEEP VISIBLE AT THE FRONT OF MEDICAL RECORDS AT ALL TIMES
DO NOT PHOTOCOPY**

Name
NHS number
Dob
Address
Post code

This child is at risk of prolonged convulsive seizures:

Rescue anticonvulsant medication is:-

Plan if rescue medication doesn't work:-

- 2.1 Transfer to** e.g. Emergency Dept / discuss with PICU / hospice
(see family 'choices' document – always call hospice before transfer there)

Ambulance staff please call ahead to alert receiving staff that this child has a personal resuscitation plan.

2.2 Who to call (with phone numbers)

If in hospital

If at home

If in school or short break unit

In the event of the need for a general anaesthetic this resuscitation plan becomes suspended for the peri-operative period. A plan agreed by the family, anaesthetist and surgical/medical teams will be documented in the medical notes to cover this period.

**PLEASE KEEP VISIBLE AT THE FRONT OF MEDICAL RECORDS AT ALL TIMES
DO NOT PHOTOCOPY**

| |
|------------|
| Name |
| NHS number |
| Dob |
| Address |
| Post code |

3. The plan has been discussed with e.g. both parents.
Consider mental capacity of child / young person and who has parental responsibility.

This plan does not expire but will be reviewed as the child’s condition changes.

The patient or parent / guardian can change their mind about any of these options at any time. If they agree with the plan verbally but do not want to sign it, then another member of the clinical team usually a senior nurse in addition to the consultant should witness that parents agreed with the plan and sign below. **The Consultant must sign the plan.**

Consultant’s agreement

I have discussed and support this Personal Resuscitation Plan / Emergency Healthcare Plan

Name & signature **date**

Parent or Guardian’s agreement

I have discussed and support this Personal Resuscitation Plan / Emergency Healthcare Plan

Name & signature **date**

Child or young person’s agreement

I have discussed and support this Personal Resuscitation Plan / Emergency Healthcare Plan

Name & signature **date**

Nurse agreement

I have discussed this plan with the child or young person / parent or guardian

Name & signature **date**

Adult Physician / GP agreement (when the young person is moving on to adult services)

I support this plan

Name & signature **date**

PLEASE KEEP VISIBLE AT THE FRONT OF MEDICAL RECORDS AT ALL TIMES
DO NOT PHOTOCOPY

This entire section is optional and can be deleted from the digital template at the time of completion if not required.

Name
NHS number
Dob
Address
Post code

4.a) Emergency care plan - Complete and delete sections as appropriate

In the event of a gradual deterioration in respiratory condition:-

Symptoms/signs to expect

Select the options needed: (Delete options not required)

1. Comfort & support child and family.
2. Airway management is very important: reposition head and neck, clear secretions, use oral/nasopharyngeal airway if it helps.
3. Give oxygen for comfort via face mask/nasal cannulae.
4. Start oral antibiotics. Parents keep antibiotics available at home.
5. Increase respiratory secretion clearance measures / chest physiotherapy.
6. Consider admission for intravenous treatment if no improvement after 48 hours or if deteriorating rapidly / distressed.
7. Consider non-invasive ventilation.
8. Endotracheal intubation & invasive ventilation should be considered / would not be appropriate.

Other symptom relief:

This child has fragile bones and must be handled very carefully. *please tick box if applicable*

PLEASE KEEP VISIBLE AT THE FRONT OF MEDICAL RECORDS AT ALL TIMES
DO NOT PHOTOCOPY

This entire section is optional and can be deleted from the digital template at the time of completion if not required.

Name
NHS number
Dob
Address
Post code

4.b) Emergency care plan - Complete and delete sections as appropriate

In the event of a gradual deterioration e.g. oncology or metabolic condition:-

Symptoms/signs to expect

Select the options needed: (Delete options not required)

1. Comfort & support child and family.
2. Follow symptom control plan / metabolic disease plan which is in the home / attached
3. Pain relief is very important - increase analgesia according to plan attached
4. Contact on call medical team for further advice
5. In the event of uncontrolled or distressing symptoms arrange admission to hospital / hospice
6. Ventilatory support should be considered / would not be appropriate.

Other symptom relief:

**PLEASE KEEP VISIBLE AT THE FRONT OF MEDICAL RECORDS AT ALL TIMES
DO NOT PHOTOCOPY**

Name
NHS number
Dob
Address
Post code

- 4.1 Transfer to** e.g. Paediatric Emergency Dept / discuss with PICU /
PICU not appropriate/ preferred ward of admission / hospice (always call ahead)

Ambulance staff please call ahead to alert receiving staff that this child / young person has a personal resuscitation / emergency health care plan

- 4.2 Who to call in the event of a gradual deterioration** (with phone numbers)

If at home:

If in school:

If in short break unit:

If in hospital:

**PLEASE KEEP VISIBLE AT THE FRONT OF MEDICAL RECORDS AT ALL TIMES
DO NOT PHOTOCOPY**

| |
|---|
| Name NHS number Dob Address Post code |
|---|

6. Copies of this plan are held by

- Parents / guardian at home address and at
- With patient at all times contact details
- School contact details
- Short break unit contact details
- Ambulance service contact details
- GP contact details
- Local Notes (CDC or community) contact details
- Community nurses contact details
- Hospice contact details
- Central Audit File contact details

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**PLEASE KEEP VISIBLE AT THE FRONT OF MEDICAL RECORDS AT ALL TIMES
DO NOT PHOTOCOPY**

These instructions on how to complete the plan should be deleted before the plan is printed and given to the family.

Background

This individual plan for emergency care and resuscitation is to ensure best care for a child or young person when they have a Life Shortening Condition or Life Threatening Condition. For some children it will be one part of an agreed "End of Life Plan".

The Personal Resuscitation Plan / Emergency Healthcare Plan is a **medical care plan** and is the responsibility of the child / young person's consultant. It is their plan of best care for their patient. It is ideally drawn up with a child / young person and their parents / guardian by a doctor who they know and who knows the child / young person's condition well. This will not always be possible, but discussions about resuscitation should not usually be the first thing mentioned when meeting the child / young person or family for the first time.

Circumstances will vary, from an intelligent, well, 14 year old with a diagnosed incurable life shortening condition to a child in deep coma ventilated on PICU with a severe accidental traumatic brain injury. In all cases the child / young person's parent or if possible both parents or legal guardian will be involved in drawing up the plan. In some cases, e.g. at the suggestion of the doctor or nurse and at the discretion of the parent / legal guardian, the child / young person may also be involved; depending on conscious level, maturity, emotional state, capacity to understand, previously expressed wishes, options available.

This plan is personal and flexible and should be used to empower children / young persons and their families; to affirm what choice / control they have, within the confines of good care. It will help communication between the child / young person and parents / guardian and medical, nursing and other professional services.

Completing the form

The blank template can be used to discuss options with families in a positive way as soon as a life threatening event or deterioration can be predicted as a possibility. They will be glad to have a family held emergency care plan for their child / young person.

The plan is the responsibility of the child / young person's lead consultant or GP and ideally it is that doctor who leads the discussions with the parents / guardian and child / young person if appropriate. The doctor needs to know the prognosis of the child / young person and to be able to predict how the child / young person may deteriorate in order to discuss with the family the best emergency care and resuscitation plan. The child / young person's community nurse will usually be part of the discussions to ensure that the care plan will work in the community setting. The consultant must sign and date the form. The child / young person and or parents / guardian can also sign, but do not need to as they can over-ride this written plan at any time for any reason, i.e. they can change their minds and verbally ask for a different action e.g. more or less intervention.

The plan is regularly reviewed by the medical care team as the child / young person's condition changes over time. The plan must be reviewed at least annually and this review must be documented in the main medical record. The plan does not have to be discussed with the family at each appointment or hospital admission. The family can ask for it to be reviewed at any time. There is no fixed review date written on the plan. The plan cannot "time expire" any more than any other documentation of a discussion about therapeutic options in the patient's notes.

Other than at the time of original distribution the plan should not be photocopied as all copies need to be identified and cancelled if the plan is revised.

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Completing the form continued:

Section 1 – Background

The reason why the child needs a resuscitation plan / emergency healthcare plan. Put the diagnoses and brief description of the patient's Life Shortening or Life Threatening Condition in the box.

Section 2 – is the resuscitation plan in the event of a respiratory or cardiac arrest and also includes the plan for seizures.

Section 4 - is the emergency care plan in the event of a deterioration which may be due to an intercurrent illness or gradual deterioration at the end stage of a life limiting condition. Put any anticipated circumstances in the boxes. Section **4a or 4b** may be appropriate for the child. Select the interventions that are needed after discussion with the parents / guardian, and child / young person if appropriate. Usually there will be time for the template to be typed to produce a clear plan where the unwanted options or sections are deleted and only the positive instructions are on it. In an emergency a handwritten version of the plan can be left with the family with the unwanted options on the template crossed through using black or blue pen. Make sure any corrections are clearly legible.

The same plan can be used at home or in school, short break unit or hospital, e.g. "mouth to mouth" in the community becomes "bag and mask" on the hospital ward. "Mouth to mouth" becomes "mouth to trachy" or "bag to trachy" for patients with a tracheostomy.

Fill in the boxes at 2.1 and 4.1 to say where, if anywhere, the child should be transferred and at 2.2 and 4.2 to say who should be called, e.g. parent and bleep children's community nurse if child is in short break unit or school, bleep community children's nurse if child at home, or if in hospital the cardiac arrest /emergency medical support team – ensuring that they are made aware of the resuscitation plan.

It may be appropriate to call 999 paramedic ambulance if the child / young person is outside hospital with uncontrolled symptoms. In which case ambulance control should be told that there is a personal resuscitation plan when the ambulance is called and ambulance staff must be given the plan on arrival - ideally the original signed plan in colour which should be with the child / young person at all times.

Some families will have completed a 'choices' document which details other aspects of their child's 'End of Life Plan'. A copy of this will be with the family and their key worker and may be filed in the main medical notes. A summary of the family choices at end of life can be recorded at **Section 5** if appropriate, and with family permission.

It is important to document who it is in the family that the plan has been discussed with and it may be helpful to record the family's understanding of the situation in **Section 3**.

If the child / young person has been involved in the discussions, usually with parent or guardian support, they can sign **Section 3**, to acknowledge this, but do not have to. Similarly the parents / guardian do not have to sign. If they agree with the plan verbally but do not want to sign it, then another member of the clinical team usually a senior nurse in addition to the consultant should witness that parents agreed with the plan and sign at **Section 3**.

The child's consultant must sign Section 3, even if the plan has been raised with the family by another senior member of the team.

The plan does not need to be reviewed at any fixed time but should be reviewed whenever the child's condition or circumstances change. It must be reviewed at least annually by the lead consultant and this must be documented in the child / young person's main medical record but does not need to be documented on the plan itself. The plan must be reviewed on discharge from hospital when consideration of where copies of the plan should be held is essential, **Section 6**.

Old versions should be crossed out with 2 bold single diagonal lines, on each page. Sign and date the crossing out. File in the back of the medical records.

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**Personal Resuscitation Plan / Emergency Healthcare
Plan process for Medical/Nursing/Secretarial Staff**

When a child, because of their medical condition, needs an emergency care/resuscitation plan, a senior member of the child's medical team and ideally the child's keyworker or community nurse should develop the plan with the family and sometimes the child/young person themselves. The use of this template to document the plan ensures it is recognised by emergency staff across the East Midlands.

The plan can be typed by the consultant directly into the PRP template on Medical Office, completing and deleting sections as appropriate. Alternatively a handwritten plan can be made and given to the family as a temporary record and for their further consideration at their leisure. A copy of that should be filed in the child's main medical record and a copy is passed to the secretary for typing into the template.

The Consultant needs to sign three typed originals of the plan printed in colour. Consultant or senior member of medical/nursing team needs to meet with the family for the parent/carer signature on each of the three originals. If amendments are made at this point, return back to secretary to make changes.

If no amendments required, the three signed and colour printed plans are: -

- 1 Stays in the family home.
- 2 Is kept with the child at all times.
- 3 Is brought back to the secretary to initiate the distribution.

If ReSPECT form has been completed attach it to the front of the plan before distribution.

Ambulance staff will follow the plan that is with the child, ideally a signed, original colour printed version. A copy of the plan can be sent to EMAS via Roger.watson@nhs.net and also their generic email - cadadmin@nhs.net.

If the plan states that the child should be transferred to the hospice it must also state that the hospice needs to be contacted prior to transfer.

Secretary:

Ensure that the hand written copy is filed at the front of the child's main medical record.

Secretary or consultant types the plan using the template on Medical Office or word document to scan onto electronic record later.

Date plan created and Consultant responsible plus 24 hour contact number for any queries about the plan needs to be on the front page.

Secretary starts a process tracking sheet in a central audit file.

Secretary:

If the copy has been signed by Consultant and parent/carer authorise on NOTIS and proceed to distribution.

If amendments are made following signing by Consultant, the Consultant makes amendments and puts an amended date on the front of the plan.

There may be several drafts before the final version is agreed and each amended copy should be kept in the notes (not at the front).

All amended copies should be crossed through with 2 diagonal lines to show that this plan has been amended and is not the up to date copy.

Secretary:

Distribution of plan as follows:

Original signed colour version of the plan which has come back with Consultant and parent signatures is used to make photocopies which are distributed according to the list on the plan itself. After distribution no further copies should be made.

The GP copy is sent the plan electronically if possible and also by post with a covering letter if appropriate requesting GP to complete the special patient notes on the GP OOH system.

Copies to be **distributed personally** by Keyworker to all other sites of care e.g School, Short Breaks Service and Community Nurses.

The original colour version is then filed at the front of the child's main medical record.

Flag and scan on to hospital / community electronic record systems (e.g. NOTIS / Medway / System One.

In the event of the death of the child/young person be sure to notify all sites holding copies of the plan including EMAS.