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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.



Transforming Children's End of Life Care

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:

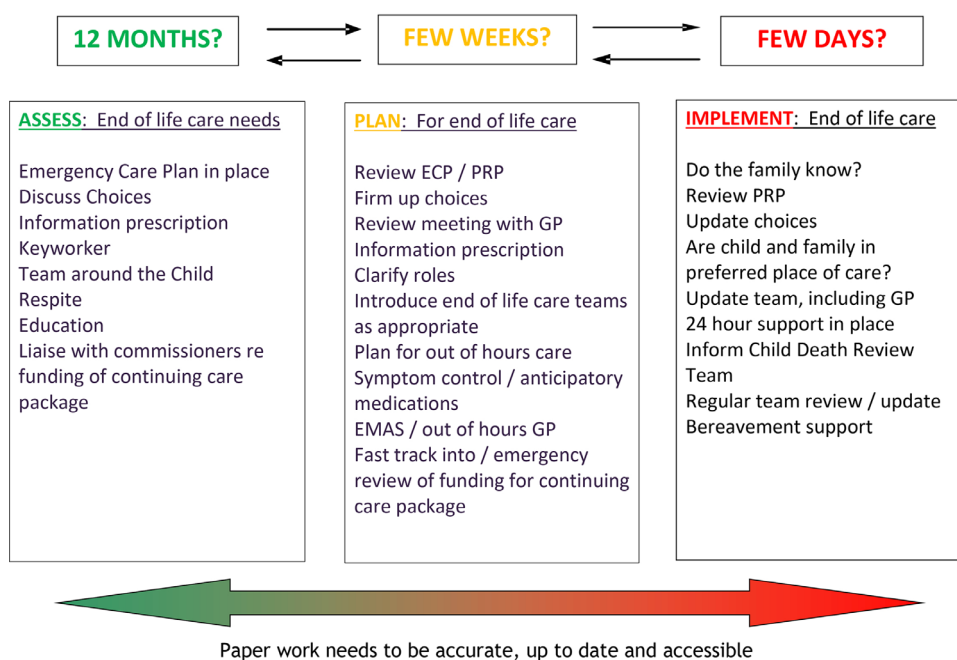


Figure 1 Prompt Tool for Children's End of Life Care Planning.

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.

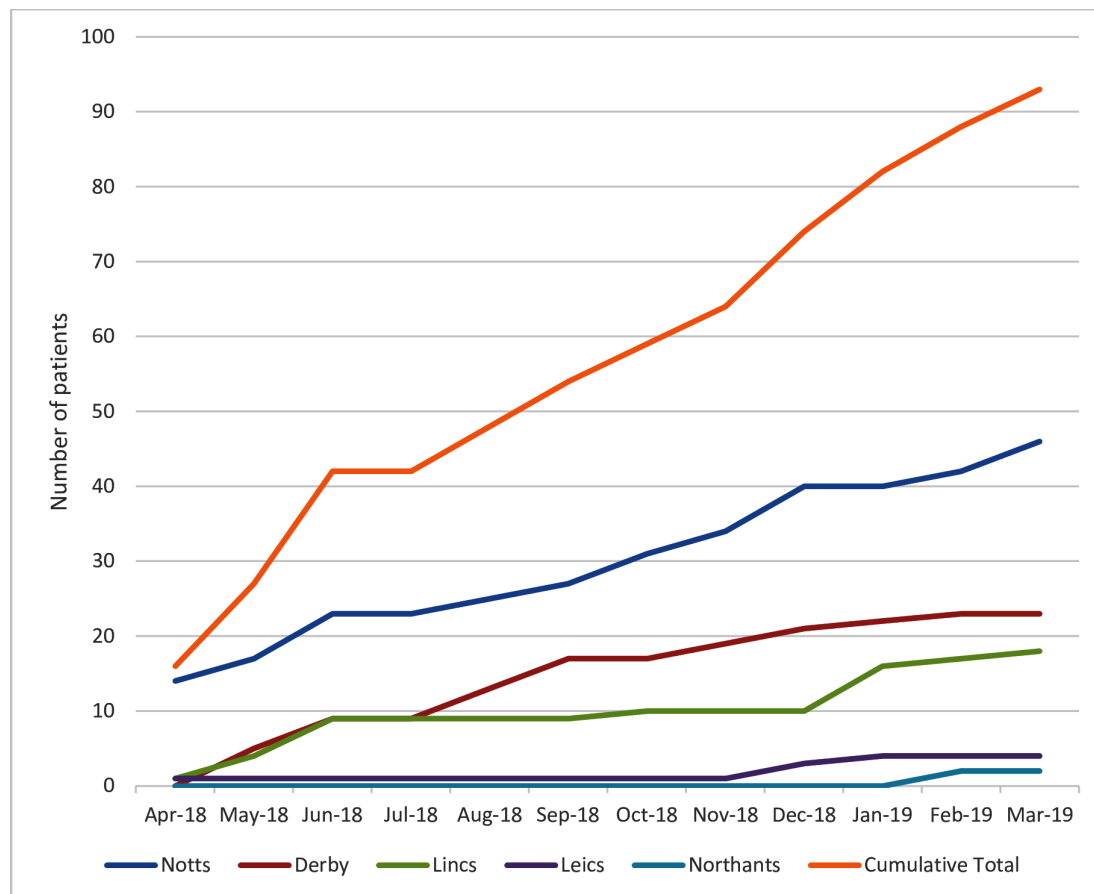


Figure 2 Cumulative data on patients identified to the Chameleon team by geographical region.

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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