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## Independent Evaluation of the Pan London Lead Nurse for Neonatal Palliative Care Project

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## Foreword

Neonatal Critical Care is a hugely technical discipline and has made great advances over the past 30 years. With that great success has come the recognition of the importance of parents in day-to-day care and the very real responsibility placed on staff to support and communicate with parents. Traditionally, neonatal training has not been directed towards this focus, but as it assumes greater importance in our more open society, good support structures and clear communication are expected.

Sadly, and despite our best efforts, babies are born with and acquire serious conditions that may not be easily treatable, and many still die. Recognising that we can do much to ease the distress felt by babies, parents and families in this emotionally fraught situation is the first step in providing world class care for this important group. Managing the process well is a measure of our compassionate care and carries the bonus that, if we can get it right, it is likely that long term adaptation for the families involved is improved. In this light it is wonderful to see the support given to professionals by the True Colours Trust, CW+ and Hospital Trusts in committing to improving neonatal palliative care in our complex national service.

This report is a success story – success that has been won by hard work and great commitment by a range of people and teams lead ably by Alex Mancini. Reading about the success of the programme in London is a truly uplifting tale in these difficult times and demonstrates the commitment that professionals have to continuous service improvement. The work described has made a real difference to all involved – babies, families and staff.

The two major recommendations – to take all steps to make this initiative sustainable and to roll it out to other Operational Delivery Networks in England and the devolved Nations – are very welcome. This facilitated model is effective. Neonatal Palliative Care has come of an age and must be here to stay.

Congratulations to all on the delivery of this important project.

Professor Neil Marlow  
University College London  
March 2021

## Introduction

### What is neonatal palliative care and why is it needed?

*“When I was first talking about palliative care on neonatal units about 15 to 20 years ago, many of my colleagues said there’s no such thing as neonatal palliative care, there’s no place for palliative care in neonatal care, there’s either death or there’s survival. I said, there’s this whole period in between...”* Alex Mancini, Pan London Lead Nurse for Neonatal Palliative Care



Neonatal palliative care is an emerging specialism. Advances in technology and medicine have made it possible to keep alive babies who would previously have died, particularly those born at very early gestational ages. In specific circumstances, initiation of life-sustaining treatment may now be considered for babies born at 22 weeks gestation.<sup>1</sup>

Although survival rates and outcomes have improved steadily over the past 25 years<sup>2</sup>, the prognosis for the youngest, smallest and sickest babies often remains uncertain. Some spend months in a neonatal intensive care unit before they are clinically stable and ready to be discharged home, or before their parents, along with the clinical team, are faced with making the very difficult decision of whether to withdraw life-sustaining treatment.

It is in this space that neonatal palliative care has grown, driven by clinicians responding to the changing needs of the babies and parents they care for, and by charities campaigning for improvements in neonatal care and children’s palliative care.

Neonatal palliative care is a broad concept, which emphasises the comfort of the baby and quality of life for the family, however long their time together may be. It includes, but is not limited to, the care provided at the end of a baby’s life. For some families, palliative care begins before the baby is born. It may be needed for a very short period of time – days or even hours – or for many years, beginning in the neonatal period. Palliative care may be delivered alongside life-sustaining treatment, involving parents in decision-making and recognising their need for emotional support.<sup>3</sup>

*“This experience defines the rest of their life. If you manage to do this well, that’s a gift that goes on for years.”* Neonatal consultant

### How many babies?

A recent study by Professor Lorna Fraser provides robust data on the number of children with a life-limiting or life-threatening condition in the UK.<sup>4</sup> The under-1 age group has by far the highest

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<sup>1</sup> BAPM (2019) *Perinatal management of extreme preterm birth before 27 weeks of gestation: A framework for practice*

<sup>2</sup> NHS (2019) *Implementing the Recommendations of the Neonatal Critical Care Transformation Review*, p.3

<sup>3</sup> Marlow N. & Gallagher K., *Introduction to Neonatal Palliative Care*, in Mancini A. (ed) 2020, *Neonatal Palliative Care for Nurses*, Springer Nature Switzerland AG

<sup>4</sup> Fraser L. et al (2020) ‘*Make Every Child Count*’ *Estimating current and future prevalence of children and young people with life-limiting conditions in the United Kingdom*

prevalence, at 226.5 per 10,000 infants (England, 2017/18). As such: “This group should be seen as a priority for receiving palliative care as the mortality rate is also highest in the under 1 age group.”

There are currently no national data on the number of babies with palliative care needs, but an exploratory analysis for this project by Dr Cheryl Battersby of the Neonatal Data Analysis Unit at Imperial College London<sup>5</sup> indicates that approximately 7 per cent of babies (approximately 4,000 out of 60,000) admitted to neonatal care in London from 2014 to 2018 inclusive fulfilled the criteria for palliative care (as defined by BAPM, 2010<sup>6</sup>). Many were discharged home, pointing to the need for continued support in the community.<sup>7</sup>

### The Pan London Lead Nurse for Neonatal Palliative Care Project

The Pan London Lead Nurse for Neonatal Palliative Care Project launched in March 2015 with funding agreed for five years from the True Colours Trust, Chelsea and Westminster Hospital NHS Foundation Trust, and its charity CW+. As well as supporting progress in London, it aimed to develop a ‘blueprint’ which could be implemented in other UK regions. The project aimed to provide:

“Strategic, inspirational and professional senior nursing leadership in the development and delivery of a multi-disciplinary neonatal palliative care service... The Lead Nurse will work in collaboration with a multi-disciplinary team in order to achieve the highest standards of optimal care for this group of babies and families. This will involve teaching and supporting the early identification of eligible babies, and ensuring they are being cared for in the most appropriate environment.”<sup>8</sup>

### Purpose and timing of this report

An independent evaluation of the project was carried out by Anne Pinney, an independent researcher, between July 2019 and January 2020, reporting in March 2020, shortly before the COVID-19 national lockdown. The evaluation report, its recommendations updated to reflect the new context of COVID-19, is published now with two aims:

1. To report on the impact and influence of the Pan London Lead Nurse for Neonatal Palliative Care
2. To inform the development of neonatal palliative care in other UK regions.

**We hope this report will be of interest to all those concerned with improving outcomes for babies with palliative care needs and their families;** in particular, senior staff in the Neonatal Operational Delivery Networks (ODNs), healthcare commissioners, senior staff in neonatal units, perinatal teams, children’s palliative care teams including children’s hospices, maternity and paediatric care, researchers, policy makers and healthcare regulators.

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<sup>5</sup> Dr Cheryl Battersby is Clinical Senior Lecturer at the Neonatal Data Analysis Unit, NIHR Clinical Scientist, Honorary Consultant Neonatologist at Chelsea and Westminster Hospital NHS Foundation Trust and BAPM Data Lead.

<sup>6</sup> British Association of Perinatal Medicine (2010) *Palliative Care (Supportive and End of Life Care) A Framework for Clinical Practice in Perinatal Medicine Report of the Working Group*.

<sup>7</sup> See Annex A, table 2, in the accompanying Evidence Supplement.

<sup>8</sup> Memorandum of Understanding between the funding partners, October 2014.

## Contents of the Evaluation Report and Evidence Supplement

**Chapter 1 considers what neonatal palliative care is, and why it matters.** It includes family case studies, research insights from Professor Jayne Price into families' experience of hospice care, and important new data on the number of babies eligible for palliative care in London. **Annex A** provides a detailed report on the data, written by Dr Cheryl Battersby of the Neonatal Data Analysis Unit, Imperial College London.

**Chapter 2 describes the work of the Pan London Lead Nurse for Neonatal Palliative Care,** including the many Study Days delivered in neonatal units across the London Neonatal Operational Delivery Network (ODN) and in children's hospices from 2015 to 2018, as well as her advisory and change leadership roles. **Annex B** reports in detail on Study Day outcomes.

**Annex C reports on how far neonatal palliative care approaches have been embedded** in the 27 neonatal units in London, and two neighbouring units in Essex involved in the project, based on an audit carried out during Summer 2019.

**Chapter 3 shares key findings from the independent evaluation,** reflecting on the project's impact on the development of neonatal palliative care in London, as well as wider factors influencing or impeding progress. It concludes with recommendations to sustain progress made in London and to prepare to extend this initiative to other UK regions, adapted to reflect the new context of COVID-19.

### Evidence base and limitations

The independent evaluation drew on a wide range of evidence, including:

- Over 900 questionnaires completed before and after Study Days, from 2015 to 2018
- An audit of neonatal palliative care provision across the London Neonatal ODN
- Data on referrals to specialist and community palliative care services in London
- Semi-structured interviews with nurses and consultants in neonatal and palliative care, hospice staff, nurse educators, and senior London Neonatal ODN staff.

Although there were some data quality issues and gaps in the evidence, every strand was consistent in demonstrating the very positive impact and influence of the Pan London Lead Nurse for Neonatal Palliative Care.

### Author's note

My thanks to the project Advisory Group for their generous advice and support. Special thanks to Dr Cheryl Battersby and Professor Jayne Price for their invaluable contributions to Chapter One. Thank you to Geraldine Cochrane who visited nearly every neonatal unit in London to complete the audit (Annex C) and Nikita Smith, for cleansing and checking all the survey data (Annex B). Thank you to Alex Mancini for her patient advice and constant inspiration, and to the True Colours Trust for all their support. Responsibility for the analysis, conclusions and any errors in this report is mine alone.  
- Anne Pinney, independent evaluator, November 2020

## Chapter 1: What is neonatal palliative care and why is it needed?

1. Families' experiences
2. What is neonatal palliative care?
3. How many babies?
4. Policy and commissioning

### 1. Families' experiences

Arguably, the key driver behind the development of neonatal palliative care has been to improve the experience of families with a baby in neonatal care, whose chances of survival are uncertain in the early days, weeks, and months of life. It seems fitting therefore to start this report with case studies kindly shared by two such families.

#### **Eva's story, in her mother's words<sup>9</sup>**

Background, with some clinical details:

Eva and Charlotte, twin girls, were born at 28+0 weeks gestation by emergency C-section after spontaneous waters broken. Their mother, Sarah, had polyhydramnios during pregnancy and suspected Twin To Twin Syndrome. Eva's tracheoesophageal fistula/oesophageal atresia was diagnosed shortly after birth when the nasogastric tube could not be passed. Eva was then transferred to a tertiary surgical neonatal unit for emergency surgery, with a ligation of the fistula. Charlotte was transferred to the same unit five days later but was never in the same room as her twin sister.

Eva's second surgery to connect the oesophagus at around ten weeks was unsuccessful. Charlotte was discharged home after 79 days, but was unable to return to the ward to visit Eva due to winter infection control restrictions. Eva continued to grow and began to thrive - smiling, gaining head control, making cooing sounds. She was fed expressed breast milk via a gastrostomy and required frequent suctioning.

Continuing in Sarah's own words:

The day of her third planned surgery, I remember sleeping at the hospital the night before and not really sleeping at all... She seemed in good spirits, she was smiling, we were cuddling and singing to her... It was always going to be a long surgery, but it had taken a little bit more time than they had anticipated... She came back to the neonatal unit and... the plan was to keep her sedated for five days because of the delicate connection on her oesophagus...

Two weeks after her operation... we had an MRI scan on her brain... At the end of that day we were called into a quiet room and I remember [the doctor] sort of holding my hand and me pulling it away - because of thinking that means she's going to tell me something bad. She said 'we've had the results of the MRI and she's had devastating global brain damage which... includes her brain stem. So she will stop breathing at some point.'

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<sup>9</sup> Verbatim extracts from an interview recorded by the Pan London Lead Nurse for Neonatal Palliative Care for a training DVD in partnership with Child Bereavement UK.

I just couldn't speak. Then I sort of said 'so she'll never wake up?' and they said 'no' and then we said, 'what do we do now?'... I'm trying to remember the exact words, but I think it was something like 'the kindest, or the only thing really, is to allow her to die.'

I think it was the next day that we had a conversation about options, about what we could do. We were given one of the parents' rooms on the unit, so we took Eva in there and we had some time alone with her. I remember sitting on the bed, we'd never done that, the two of us - it's such a normal thing to lie on a bed holding your baby... I was very grateful for the people around us, who kind of guided us through what was going to happen, because I kept thinking 'I don't know what to do for the best, what do people normally do in this situation? I need somebody to tell me what to do...' Then somebody said 'oh, you might want to give her a bath or a wash...' and I thought 'yes, that's exactly what I want to do' but I wouldn't have thought of it. We were basically told we had three options, to keep her in hospital and to take her off the ventilator in hospital, to take her home or to take her to a hospice...

We went to visit Shooting Star [hospice], while she was still in hospital. It was just such a lovely place... you can feel it when you walk through the doors, it's such a warm, positive, happy place and bright and just a nice environment. We met somebody there and we were shown around, and we were shown the cold room. I'm one of those people who like to be prepared... so that really helped me to see the room, to see the parents' accommodation.

Dave (her father) really wanted to bring her home. I was worried and I asked about what support we would get at home, and we were told that the community nurses would come every day, and we would be trained on feeding, and that there would be... this Great Ormond Street phone number, that I could call at any time of night with questions about anything. So that really reassured me that the support wouldn't just disappear if we went home... We were at home with her for three days, so we were able to get some photographs with the four of us together... We had a lot of support at home, which I was grateful for.

We talked about what would happen when she actually did die... and all of the things that happened, we were sort of slightly prepared for... She stopped breathing, in my arms... Dave was with me. I can't put into words how I felt at that moment... but I remember thinking 'is this it? Is this really it?' and then knowing that it was. So we dressed her and washed her then I remember I kissed all of her scars. We didn't rush...

We arranged for the funeral people to transport her to Shooting Star and we drove there, because I wasn't ready to let her go somewhere else, I wanted to be in the same place as her. So we were able to see her in the cold room at Shooting Star, we were able to sleep a little bit, we had Charlotte with us of course, so she was able to sleep in a cot next to us in a room. I'm very grateful that we, the four of us, were together...

Family and the nurses from the hospital, who by that point were like family, were able to come to Shooting Star and came in to see her and say goodbye. We did footprints, which I really cherish. Shooting Star subsequently have been fantastic support for quite a long time afterwards... I wasn't expecting so much of that incredible follow-up care.

## **Charlie's story, in his mother's words<sup>10</sup>**

Our lives changed unimaginably with the birth of our second son, Charlie. It was a traumatic delivery which required significant resuscitation and left him severely brain damaged.

On top of obviously dealing with all the grief of the life that we'd imagined, was also dealing with how were we going to manage his care, how were we going to pay the mortgage? I was drowning under piles of paperwork - of referrals, of appointments, of Disability Living Allowance forms...

Immediately through that process, Haven House (children's hospice) started to support us. Becky, the family support worker, helped me really navigate my way through that and really see the wood for the trees and understand how I could start to take us in a more manageable direction.

I'd completed an extensive list of competencies in order to manage Charlie's care. He requires tube-feeding and learning how to use that equipment and his medication management, his additional tube management - for medications, suctioning, airway management, oxygen management - but alongside that, also caring for our other son, our then-2½ year old Dillon.

Over the first month, the nursing agency... commissioned with Charlie's care had a really bitty rota for us, leaving me awake for 36 hours straight on numerous occasions and leaving me feeling a bit doolally, it was a really tough time. I had an unsettled 2-year old, I had a baby requiring a massive amount of care, I had a husband who was at work because actually he'd used all of his sick leave and holiday and we couldn't afford for him not to be working...

Haven House offered us step-down care as part of this process, in trying to really enable us to find our feet. Unfortunately, after three days Charlie was readmitted to hospital. When we were finally discharged again, Haven House offered us 'hospice at home'... Offering us things like the play services at home, enabling somebody to be giving Dillon some attention... enabled me to find my feet. The fact that it was at home in our own environment, with me finding my feet and working with what we have around us, rather than us being somewhere else, was actually really important as part of that.

We don't drive and Charlie's got lots of heavy equipment and so it means we're going out with the buggy fully laden up, incredibly heavy, needing two hands to push it... I was left really feeling like we couldn't leave the house, which meant that we wouldn't have been able to access any of Charlie's therapies and they've been so hugely beneficial to us. He has music, physiotherapy, yoga - all of this input that has enabled us to really see a transition towards him becoming more alert and developing, but also keeping his body relaxed and not tight and painful, and improving his breathing. You know it's been hugely important to us. We have the toy home loan service on top of that, so that we can then try and see what Charlie likes...

I'm really in awe of how holistic Haven House's approach is and how they've managed to support every element of our lives really - and I don't think that we would be here if we hadn't had that, so I really can't thank them enough.

**Families' experiences of neonatal palliative care remain under-researched, but Professor Jayne Price of Kingston University and St George's, University of London has kindly provided a Research Insight (box below), drawing on her recent research. The findings provide important insights into neonatal**

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<sup>10</sup> Transcribed with kind permission from Charlie's mother, Ananda. Verbatim extracts (reduced slightly in length) from a video published on YouTube for Haven House, a children's hospice involved in this project <https://youtu.be/v0EVLAbLqus>.

palliative care from the perspective of professionals and parents, particularly around decision-making, care and support within children's hospices.

### Research Insight: Evidence from the Neonatal Palliative Care in Hospice (NePaCH) study, 2019

*Kindly summarised here by Professor Jayne E. Price, Professor of Children's Nursing at Kingston University and St George's, University of London.*

**About the research:** Qualitative methodology examined experiences of staff (n=17) using focus groups and bereaved parents (n=5) through face-to-face in-depth interviews recruited through three children's hospices within the London area. Services used included 'in-house' for end of life care, special bedroom, bereavement care and family support. Ethical approval was granted and ethical considerations were paramount in all stages of the research.

**Emerging messages:** Thematic analysis on parents' data gave rise to four distinct but inter-related themes which help us to better understand parents' experiences of living through the loss of a baby:

1. Life-changing news
2. What if?
3. Hello and goodbye
4. Being together and being supported.

Such themes gave invaluable insight into the emotional/practical chaos and uncertainty associated with the shock and realisation that their baby was going to die, and revealed key elements that make neonatal palliative care, particularly within children's hospices, instrumental in supporting families in the perinatal/neonatal period.

#### Implications for practice

- Uncertainty was somewhat eased with advance planning with expert professionals for each possible outcome, so there was a plan for each 'what if?'
- Providing timely information to parents was crucial to enable them to make choices
- Choices and decision-making were central to parent stories.

*"We are grateful for a lot of things like we...we got more, more than we'd ever hope for, 'cause we'd hoped for an hour, maybe two, [that] was the most we would ever allowed ourselves to think we would get with her, and we got three, three and a half days, which a lot of people don't get. I guess 'cause we'd had all the team involved from during pregnancy, that's the main thing that helped things go so smoothly as they could. When she was born, 'cause then there wasn't a rush so when she started showing any sign of distress, they didn't have to go and get a doctor to write things up, 'cause it was already all done." (Mother from NePaCH, 2019)*

The word 'hospice' came with negative connotations when first mentioned to parents. The reality was much better than parents imagined and was not the dismal, dark place where dying occurred - rather the bright place where living happened, and memories were made in an environment that in many ways mimicked home, with clinical expertise on hand.

This study showed that parents had many options when facing the painful loss of their baby, so close to birth. Whilst neonatal units will remain the place of death for some babies, hospice and home are real options for others, but unfortunately not all parents are aware of this.

*“...once it was quite clear that Jay\* wasn’t going to have long-term care there, they moved us to a really private area so we had .... I mean it was still within the intensive care area, but it was relatively private and we didn’t have any other babies right next to us, and they gave a couple of sofas to sit in there next to him and were really good at having lots of visitors, so although that was much better, it was still within the intensive care unit, there were still the other people around and it just didn’t feel like a particularly nice environment we would want to be in.” (Mother from NePaCH, 2019; \*name changed.)*

Journal article: Mendizabal-Espinosa, RM and Price, JE (2020) *Family centred: neonatal palliative care in children's hospices: A qualitative study of parents' experiences*. Journal of Neonatal Nursing (in press) published online September 2020.

## 2. What is neonatal palliative care?

### Neonatal care in the UK: an introduction

Around one in seven babies in the UK (nearly 105,000 in 2018) need specialist neonatal care because they are born prematurely, with too low a birth weight or a condition that requires specialist treatment.<sup>11</sup> Most are discharged within a week, but those with the most complex needs, requiring continuous supervision, ventilation and tube-feeding may spend several months in neonatal intensive care.

Since 2003, neonatal care has been organised into networks of hospitals, which work together to provide ‘pathways of neonatal care.’ The aim is for babies to be cared for as near to home as possible, depending on the level of specialist care required. Each network has at least one Neonatal Intensive Care Unit (NICU, also called level 3 units) with two other tiers of support provided by Local Neonatal Units (LNU, level 2 units) or Special Care Baby Units (SCBU, level 1 units) in local hospitals.

Neonatal units work together to provide ‘step-down care’ for their local population of babies who have been treated in a higher level unit, as part of their journey to discharge. They also provide outreach services to support the transition from hospital to home, for example to help parents to develop the skills and confidence to cope with tube-feeding and suction.

Neonatal services in England are organised into ten neonatal Operational Delivery Networks (ODNs). Their remit is to improve access to specialist resources, neonatal outcomes and patient experience, working closely with providers and commissioners. London is by far the largest neonatal ODN, containing three clinical networks within it.<sup>12</sup>

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<sup>11</sup> National Neonatal Audit Programme (NNAP) 2019 annual report using 2018 data. RCPCH: London, 2019.

<sup>12</sup> NHS (December 2019) *Implementing the Recommendations of the Neonatal Critical Care Transformation Review*, p6-7. Neonatal services and paediatric palliative care services in London are described in the Evidence Supplement: Annex C.

## Neonatal palliative care

Over the last 25 years, the prospects for babies born very prematurely, with congenital anomalies requiring surgery or who become ill after birth, have improved greatly.<sup>13</sup> In specific circumstances, life-sustaining treatment may now be considered for babies born at 22 weeks gestation.<sup>14</sup>

Neonatal palliative care may be considered if a foetus or baby has a life-threatening or life-limiting condition, defined by the British Association of Perinatal Medicine (BAPM) in 2010, with reference to five categories:<sup>15</sup>

1. An antenatal or postnatal diagnosis of a condition which is not compatible with long term survival.
2. An antenatal or postnatal diagnosis of a condition which carries a high risk of significant morbidity or death.
3. Babies born at the margins of viability, where intensive care has been deemed inappropriate.
4. Postnatal clinical conditions with a high risk of severe impairment of quality of life and when the baby is receiving life support or may at some point require life support.
5. Postnatal conditions which result in the baby experiencing “unbearable suffering” in the course of their illness or treatment, where palliative care is in the baby’s best interests.

## Definitions

Neonatal palliative care is a broad concept, which emphasises the comfort of the baby and quality of life for the family, however long their time together may be. It includes, but is not limited to, the care provided at the end of a baby’s life. For some families, palliative care begins before the baby is born. It may be needed for a very short period of time – days or even hours – or for many years, beginning in the neonatal period.

‘Parallel planning’ for all eventualities is integral to this approach. Put simply, this allows parents and clinical teams to hope for the best possible outcome, whilst ensuring they are prepared for the worst. Palliative care may be delivered alongside life-sustaining treatment, involving parents in decision-making and recognising their need for emotional support.<sup>16</sup>

Palliative care is often confused with end of life and bereavement care. Research indicates that some healthcare professionals associate palliative care first and foremost with death and dying,

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<sup>13</sup> Ibid (p.3)

<sup>14</sup> In discussion with parents and based on a careful risk assessment. The BAPM guidance uses the term ‘severe impairment’ to include any of: severe cognitive impairment, severe cerebral palsy and/or blindness or profound hearing impairment. BAPM (2019) *Perinatal management of extreme preterm birth before 27 weeks of gestation: A framework for practice*.

<sup>15</sup> BAPM (August 2010) *Palliative Care (Supportive and End of Life Care) A Framework for Clinical Practice in Perinatal Medicine Report of the Working Group*.

<sup>16</sup> Marlow N. & Gallagher K., *Introduction to Neonatal Palliative Care*, in Mancini A. (ed) 2020, *Neonatal Palliative Care for Nurses*, Springer Nature Switzerland AG

which can act as a barrier to timely referral.<sup>17</sup> Some neonatal units and palliative care teams prefer to use terms such as ‘comfort care’ and ‘symptom management’. The latest BAPM guidance on the management of extreme preterm births describes palliative care as ‘comfort focused’, as opposed to care which is ‘survival focused’, acknowledging that these terms are imperfect.<sup>18</sup>

Leading children’s palliative care charity, Together for Short Lives, uses this definition:

*“Palliative care for babies, children and young people with life-limiting conditions is an active and total approach to care, from the point of diagnosis or recognition, throughout the child’s life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child/young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.”*

This approach strongly emphasises the role of parents “as partners in all care and decisions involving their child” and the importance of child-centred care, whether in hospital, a hospice environment or the family home. The home should “remain the centre of caring whenever possible, if this is what the family want.”<sup>19</sup>

### An emerging specialism

*“When I was first talking about palliative care on neonatal units about 15 to 20 years ago, many of my colleagues said there’s no such thing as neonatal palliative care, there’s no place for palliative care in neonatal care, there’s either death or there’s survival. I said, there’s this whole period in between...”*  
Alex Mancini, Pan London Lead Nurse for Neonatal Palliative Care

Children’s palliative care in the UK began to emerge in the 1960s and 1970s with the first children’s hospice (Helen House in Oxford) established in 1982 and the first hospital team (the Symptom Care team at Great Ormond Street Hospital) in 1986.<sup>20</sup>

Neonatal palliative care is a more recent development, as advances in technology and medicine have made it possible to keep alive babies who would previously have died, particularly those born at very early gestational ages. Although survival rates and outcomes have improved steadily over the past 25 years<sup>21</sup>, the prognosis for the youngest, smallest and sickest babies often remains uncertain. Some spend months in a neonatal intensive care unit before they are clinically stable and able to be discharged home, or before their parents, along with the clinical team, are faced with making the very difficult decision to withdraw life-sustaining treatment.

It is in this space that neonatal palliative care has grown, driven by clinicians responding to the changing needs of the babies and parents they care for, and by charities campaigning for improvements in neonatal care and children’s palliative care.

*“I used to be the only one in this unit banging on about this and now it’s a recognised part of what you do as a neonatal consultant.”* Neonatal consultant

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<sup>17</sup> Twamley K., Craig F. et al (2014) *Underlying barriers to referral to paediatric palliative care services: Knowledge and attitudes of health care professionals in a paediatric tertiary care centre in the United Kingdom*, Journal of Child Health Care

<sup>18</sup> BAPM (2019) *Perinatal management of extreme preterm birth before 27 weeks of gestation: A framework for practice*.

<sup>19</sup> Together for Short Lives (2017) *A Perinatal Pathway for Babies with Palliative Care Needs* (superseding the ACT Neonatal Pathway, 2009).

<sup>20</sup> <http://www.icpcn.org/a-global-history-of-childrens-palliative-care/>

<sup>21</sup> NHS (2019) *Implementing the Recommendations of the Neonatal Critical Care Transformation Review*, p.3

This represents a significant and ongoing cultural change in neonatal intensive care, although much variation in practice persists.<sup>22</sup>

At the same time, many children's hospice services and paediatric palliative care teams have extended their services both to antenatal referrals and babies with life-limiting conditions, supporting families' choices in making plans for birth, going home, or to a hospice service or a local hospital. A wide range of support may be required, including: anticipatory symptom management, 'step-down care' to help parents to develop the skills and confidence to cope with complex healthcare needs at home, clinical care for the baby, access to therapies, psychological support and respite for parents, sibling support and play, as well as end of life and bereavement services, and care after death for the baby and their family.

### 3. How many babies?

A recent study by Professor Lorna Fraser estimated the number of children with a life-limiting or life-threatening condition over the last 17 years, finding that the under-1 age group had by far the highest prevalence, at 226.5 per 10,000 infants in 2017/18. As such: *"This group should be seen as a priority for receiving palliative care as the mortality rate is also highest in the under 1 age group."*<sup>23</sup>

There are currently no national estimates of the number of babies in neonatal units who are eligible for palliative care. However, there are rich data to draw from, as UK neonatal services report clinical data using a universal electronic patient record (Badgernet), with data flowing to the National Neonatal Research Database (NNRD). This is held by the Neonatal Data Analysis Unit (NDAU) at Imperial College London, who kindly extracted data for this evaluation. This means that this evaluation report is able to share, for the first time, an estimate of the number of babies eligible for palliative care in neonatal units in London.

#### **Research Insight: Analysis of the cohort of babies who met the BAPM eligibility for palliative care in 2014-2018, in the London Neonatal ODN**

*Extract from an article (shown in full in the Evidence Supplement: Annex A) by Dr Cheryl Battersby, Clinical Senior Lecturer at the Neonatal Data Analysis Unit, Imperial College London, NIHR Clinical Scientist, Honorary Consultant Neonatologist at the Chelsea and Westminster Hospital NHS Foundation Trust, and BAPM Data Lead.*

**Aim:** The British Association of Perinatal Medicine (BAPM) provides a framework for palliative care, suggesting five categories of babies who should be considered for perinatal palliative care.<sup>24</sup> The aim of this analysis was to establish the cohort of babies who meet the BAPM eligibility for palliative care. This will provide an indication of the needs and palliative care resources necessary to support families.

**Methods:** Data was extracted centrally from the National Neonatal Research Database (NNRD) by the Neonatal Data Analysis Unit, for babies of all gestational ages admitted to neonatal care in London during a five-year period, 2014 to 2018 inclusive.

<sup>22</sup> Annex C: Audit of neonatal palliative care across the London Neonatal ODN (Evidence Supplement) provides evidence of the variation in practice. See also Marlow N. & Gallagher K. (2020) *Introduction to Neonatal Palliative Care* (1.1) in Mancini A. (ed) 2020, *Neonatal Palliative Care for Nurses*, Springer Nature Switzerland AG.

<sup>23</sup> Fraser L. et al (February 2020) *'Make Every Child Count' Estimating current and future prevalence of children and young people with life-limiting conditions in the United Kingdom* (published online)

<sup>24</sup> BAPM (2010) *Palliative Care- A Framework for Clinical Practice in Perinatal Medicine*

BAPM does not specify the conditions or circumstances that would be included in each category. For example, there is no consensus list of diagnoses regarding which conditions are not compatible with long-term survival (Category 1) or unbearable suffering (Category 5). With advances in medical care and provision of community support, an increasing number of babies with conditions previously considered lethal are now surviving for longer.

This study was intended as a preliminary scoping exercise to examine the feasibility of using the NNRD to quantify the population of babies who would benefit from palliative care support. For the purposes of this study, we set up definitions for each category *a priori*, accepting that these by no means represent the granularity necessary. We identified variables held on the NNRD that could be used as a proxy to represent complex and palliative care needs. Further work is recommended through a stakeholder group to develop a consensus decision as to which specific conditions fulfil BAPM categories 1-5.<sup>25</sup>

**Results:** During a five-year period (2014-2018 inclusive), 59,780 babies of all gestational ages were admitted to neonatal units (NNU) in London, with at least one day cared for on the neonatal unit.

- 43 babies fulfilled BAPM Category 1 (not compatible with long-term survival). Of these babies, 40% died in NNU, 40% were discharged home.
- 1,391 babies fulfilled BAPM Category 2 (high risk of significant morbidity or death). 10% died in NNU, 46% were discharged home.
- 6 babies fulfilled BAPM Category 3 (limits of viability; we defined this as born less than 23 weeks and admitted to a neonatal unit). 50% died in NNU, 33% were discharged home.
- 1,293 babies fulfilled BAPM Category 4 (high risk of severe impairment of quality of life and requiring ongoing support). These include 1,000 babies with recorded brain injuries, 169 babies with a tracheostomy, 84 with a gastrostomy and 86 with a ventriculo-peritoneal shunt, at some point during their admission. Of these babies, 17% died in NNU and 65% were discharged home.
- 1,422 babies fulfilled BAPM Category 5 (“unbearable suffering”; we used a proxy for complexity preterm and term babies who were in-patients at 44 weeks postmenstrual age). 4% of these babies died in NNU, 69% were discharged home.

**Findings:** Over 4,000 (7%) babies admitted to neonatal care in five years from 2014 to 2018 fulfilled BAPM Categories 1-5 for palliative care. Many of these babies with complex needs are discharged home, suggesting that there would be a need for support in the community. The highest NNU mortality was among those in BAPM Category 3 (less than 23 weeks gestation), although numbers are small. Even for those babies in BAPM Category 1, deemed not to survive in the long-term, 40% are discharged home. Around 65-70% of those babies who are likely to have impaired quality of life are also being discharged from neonatal care.

**Next steps:** This is the first study to quantify palliative care needs across a region using an established database that captures all admissions to neonatal care. We have demonstrated that it is feasible to use the NNRD to identify babies with complex needs and suggest a more comprehensive study is necessary to confirm these findings. We recommend:

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<sup>25</sup> See recommendation (i) at the end of this Research Insight.

1. A consensus decision be made regarding which specific conditions fulfil BAPM Categories 1-5. We suggest involvement of a wide stakeholder group including neonatal health professionals, hospices, palliative care teams and parents.
2. The neonatal electronic patient record (EPR) separates hospice from hospital in the discharge destination. We have put forward this suggestion for the Neonatal Dataset revision.
3. New data items be added to the Neonatal Dataset to capture whether the baby was identified as having palliative care needs, which BAPM category, whether a plan has been made with the parents, and whether the baby had a palliative or end of life care plan in place at the time of discharge.

Building on this exercise, NDAU colleagues hope to produce regional and national estimates, and to recommend improvements in the way data on babies eligible for palliative care are recorded in the Neonatal Dataset, in consultation with an expert stakeholder group. This is a positive outcome from this project, which should help to raise awareness of the needs of these babies and their families, to inform improvements in care and the planning and commissioning of neonatal services.

#### 4. Policy and commissioning

The first national guidance in this field was an ethical framework for critical care decision-making in foetal and neonatal medicine, published in 2006 by the Nuffield Council on Bioethics. This put the best interests of the baby at the centre of decisions to continue, withhold or withdraw treatment.<sup>26</sup>

In 2008, the Department of Health launched a national strategy on children's palliative care (Better Care, Better Lives). Although this did not focus on neonatal care, it noted:

*"We must face up to the challenges that currently make it difficult to provide the most effective support for families. These include: the change in the profile of children with life-limiting or life-threatening conditions over the last 20 years due to technological advances and increased survival rates of low-birthweight babies..."*

The £30 million grant programme that followed included funding for a successful pilot neonatal palliative care education programme in London, the precursor to this project.<sup>27</sup> It also funded the development of the first national guideline on neonatal palliative care (published in 2014), led by Alex Mancini and the wider clinical team, including a clinical psychologist and head of the multi-faith chaplaincy team at Chelsea and Westminster Hospital NHS Foundation Trust, in collaboration with the RCPCH.<sup>28</sup>

The first, and possibly only, clear reference to neonatal palliative care in Government policy dates back to 2009, in the seminal NHS toolkit for high-quality neonatal services.<sup>29</sup> This set out clear

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<sup>26</sup> Nuffield Council on Bioethics (2006) *Critical care decisions in fetal and neonatal medicine: ethical issues*

<sup>27</sup> Described further in Chapter 2 of this report and in Twamley K, Kelly P et al (2012), *Palliative care education in neonatal units: impact on knowledge and attitudes*, BMJ Supportive & Palliative Care

<sup>28</sup> Mancini A., Uthaya A., Beardsley C., Wood D. & Modi N. (Feb 2014) *Practical guidance for the management of palliative care on neonatal units*, RCPCH and Chelsea & Westminster Hospital NHS Foundation Trust

<sup>29</sup> <http://www.londonneonatalnetwork.org.uk/wp-content/uploads/2015/09/Toolkit-2009.pdf>

national expectations that palliative care should be integral to quality neonatal services. In particular:

- *Commissioners should ensure that services on which the neonatal service relies are commissioned as part of that pathway. This includes... palliative care [para 3.15]*
- *Each unit has an identified lead professional for... palliative care [2.8.5]*
- *Families (including the baby's siblings) are able to easily access psychological and social support and parents are given written information (in languages and formats appropriate to the local community) about relevant services covering at least... palliative care services [3.12].*

Sector charities have played an active role in raising the profile of neonatal palliative care in recent decades, working in partnership with families, clinicians and other healthcare professionals to develop tools to support improvements in practice, notably:

- The Sands Guidelines on Pregnancy Loss and the Death of a Baby (first published 1991; 4<sup>th</sup> edition, 2016)<sup>30</sup>
- The BLISS Baby Charter (first edition, 2005) and Family Friendly Accreditation Scheme (2015). These promote family-centred care for premature and sick babies, with a standard (2.5) devoted to palliative and end of life care.<sup>31</sup>
- The ACT Neonatal Pathway for Babies with Palliative Care Needs (2009), updated in 2017 in the Together for Short Lives (TfSL) Perinatal Pathway for Babies with Palliative Care Needs<sup>32</sup>.

Another influential publication was the '*Framework for practice: Making decisions to limit treatment in life-limiting and life-threatening conditions in children*', developed by leading clinicians in this field on behalf of the RCPCH (Larcher et al, 2015).<sup>33</sup>

Lastly, the National Institute for Health and Care Excellence (NICE) issued a guideline in 2016 (updated 2019) and quality standard in 2017 on '*End of life care for infants, children and young people with life-limiting conditions*'.<sup>34</sup> These set out clear expectations, including:

- Advance care planning
- Emotional and psychological support
- Symptom management
- Care delivered at home including specialist nursing and 24/7 access to advice from a consultant in paediatric palliative care
- Bereavement care and support.

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<sup>30</sup> Sands is a leading UK stillbirth and neonatal death charity <https://www.sands.org.uk/professionals/bereavement-care-resources/sands-guidelines-4th-edition>

<sup>31</sup> BLISS campaigns for improvements in the care of premature and sick babies as well as supporting families. See <https://www.bliss.org.uk/health-professionals/bliss-baby-charter>.

<sup>32</sup> Together for Short Lives campaigns on behalf of children with life-limiting and life-threatening conditions. The charity was launched in 2011 following the merger of ACT and Children's Hospices UK.

<sup>33</sup> Larcher V., Craig F. et al (2015) *Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice* [https://adc.bmj.com/content/archdischild/100/Suppl\\_2/s1.full.pdf](https://adc.bmj.com/content/archdischild/100/Suppl_2/s1.full.pdf)

<sup>34</sup> <https://www.nice.org.uk/guidance/ng61>. Although NICE guidelines are not statutory requirements, 'local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it.'

## Commissioning

One of the children’s hospices involved in this evaluation reported that that the NICE guideline led to improvements in commissioning in their area. However, commissioning arrangements remain fragmented, with aspects of neonatal palliative care funded by:

- NHS England Specialised Commissioning (neonatal critical care): “The scope of the service ranges from birth and admission... to discharge home or transfer to other services, and, increasingly, support during transition to home”<sup>35</sup>
- Clinical commissioning groups (CCGs), for example, children’s community nursing teams and individual Continuing Care packages<sup>36</sup>
- Charitable funding (whole or part) for many hospice services.

The NHS long-term plan (2019) declared that children’s palliative and end of life care is an important priority and committed to double NHS funding for children’s hospices (by match-funding CCG increases) to £25 million a year by 2023/4.<sup>37</sup>

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<sup>35</sup> Neonatal Critical Care Transformation Review – Evidence review (October 2017) para 2.1 unpublished

<sup>36</sup> DH (2016) *National Framework for Children & Young People’s Continuing Care*. Guidance for CCGs on funding healthcare packages for children and young people (aged 0-18) with complex needs, no specific mention of babies/ infants/ neonates.

<sup>37</sup> NHS England (2019) *NHS Long-term plan*, para 3.41

## Chapter 2: Role of the Pan London Lead Nurse for Neonatal Palliative Care

1. Background
2. Aims
3. Activities
4. Professional skills and experience
5. Monitoring and evaluation
6. Governance
7. Sustainability

### 1. Background

The development of this role built on the long-standing professional interest of the Pan London Lead Nurse for Neonatal Palliative Care, Alex Mancini, developed over many years as a senior neonatal nurse; a successful education pilot programme funded by the Department of Health in 2010 (part of a £30 million investment in children's palliative care)<sup>38</sup>; and the pro-active support of the True Colours Trust, whose trustees were among the first to recognise the need for neonatal palliative care in the UK.

Following many years as Matron in the Neonatal Intensive Care Unit at Chelsea and Westminster Hospital, in 2012, Alex Mancini was appointed as Neonatal Complex, Palliative and Bereavement Care Specialist Nurse, the first role of its kind nationally, which remains a substantive post on the Neonatal Intensive Care Unit at Chelsea and Westminster Hospital.

In the same year, the True Colours Trust hosted a roundtable discussion with experts from health, academia, and the voluntary sector to explore what could be done to improve neonatal palliative care in the immediate, short-term, and longer-term. The insights and recommendations that emerged from this discussion led True Colours to invite Alex Mancini to submit a proposal and business plan for a new regional post in London.

It was agreed from the outset, for reasons of sustainability, that the post should be co-funded by charitable and statutory sources. It was hoped that the London Neonatal Operational Delivery Network (ODN) would provide matched funding, as the logical partners for such a regional improvement initiative. Although they were unable to fund the project, they have provided robust, invaluable, and essential support throughout. In 2014, Chelsea and Westminster Hospital NHS Foundation Trust came on board as a funding partner with its charity, CW+. The pilot launched in March 2015, hosted at Chelsea and Westminster Hospital NHS Foundation Trust, with funding agreed for five years.

### 2. Aims

The high-level aims for the Pan London Lead Nurse for Neonatal Palliative Care were:

1. To reduce inefficiencies in delivering consistent high-quality neonatal palliative care, and facilitate smooth care pathways for each baby and their family

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<sup>38</sup> *Better Care, Better Lives* (DH, 2008). More detail on the pilot education programme is provided later in this chapter (section 3.1).

2. To provide practical support for staff working across disciplines, and develop robust working relationships across service boundaries to facilitate integrated care
3. To develop an equitable service across London, and empower families to have choice regarding the care of their baby.

This was to be achieved through “Strategic, inspirational and professional senior nursing leadership in the development and delivery of a multi-disciplinary neonatal palliative care service... The project will facilitate expert and autonomous nursing care and the provision of support to neonates, families and unborn babies who require palliative and end of life care. The Lead Nurse will work in collaboration with a multi-disciplinary team in order to achieve the highest standards of optimal care for this group of babies and families. This will involve teaching and supporting the early identification of eligible babies, and ensuring they are being cared for in the most appropriate environment.”<sup>39</sup>

It was agreed that the role would initially operate across London, with a view to replicating the initiative in other regions, in the longer term.

### 3. Activities

This has been a wide-ranging role, summarised here under three headings.

#### 3.1 Education and training

A rolling programme of education and training delivered in nearly every neonatal unit in the London Neonatal ODN<sup>40</sup>, two nearby units in Essex, and children’s hospice services across the region, was central to the delivery of this project.

The Study Days built on the successful formula developed in an education pilot programme, co-developed with Dr Finella Craig (Consultant in Paediatric Palliative Medicine at the Louis Dundas Centre, Great Ormond Street) through the 2010 DH Children’s Palliative Care grant programme.<sup>41</sup> Each Study Day:

- Was delivered on site at the hospices and neonatal units, free of charge
- Brought together neonatal, maternity and palliative care clinicians, allied health professionals and others in this field. Neonatal nurses were the main target audience, as the principal care givers in neonatal units, who develop strong relationships with families.
- Was tailored to ensure relevance to the babies cared for there, with speakers drawn from local hospice, community and specialist palliative care teams, and charities
- Was delivered on a rolling basis, at least once a year, given the high level of vacancies in London’s neonatal nursing workforce.<sup>42</sup> One of the Level 3 units in London included this programme in their mandatory training, hosting three sessions a year.

Training dates were offered approximately three to four months in advance, to enable workforce planning when releasing staff to attend. The host unit was asked to provide a suitable room and to

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<sup>39</sup> Memorandum of Understanding between the Chelsea and Westminster Hospital NHS Foundation Trust, CW+ the Chelsea and Westminster Health Charity and the True Colours Trust, October 2014.

<sup>40</sup> One neonatal unit (of the 29 involved in this project) declined to engage in this phase.

<sup>41</sup> An evaluation found that the participants “achieved a substantial increase in knowledge of services, confidence in referring to these services as well as a reported change in attitudes towards palliative care” and recommended “such a half-day locally delivered programme as a first step in facilitating access and utilisation of a variety of palliative care services.” Twamley K, et al. *BMJ Supportive & Palliative Care* 2012;00:1–8. doi:10.1136/bmjspcare-2012-000336

<sup>42</sup> NHS England (Dec 2019) *Implementing the Recommendations of the Neonatal Critical Care Transformation Review*, p.13

advertise the training within their own Trust, including in Maternity and Paediatrics. Study Days were also advertised on the London Neonatal Network website and by email to contacts across London.

Hospital Study Days were four hours long (as in the successful pilot), while the hospices preferred to host a full day of training on site. Attendance was encouraged by counting towards nurses' continuous professional development (CPD) hours and NMC revalidation.<sup>43</sup> Medical staff could also include their attendance within their required CPD.

A sample programme is shown below.



London Neonatal  
Operational Delivery Network

**Neonatal Complex & Palliative Care**  
 Services & resources to enhance support for families & professionals  
 All neonatal, maternity and paediatric staff WELCOME



**Royal London Neonatal Unit**  
 Thursday 3<sup>rd</sup> November 2016  
 8.30am – 1pm  
 Venue: Ward 8d  
 8<sup>th</sup> Floor, Central Tower

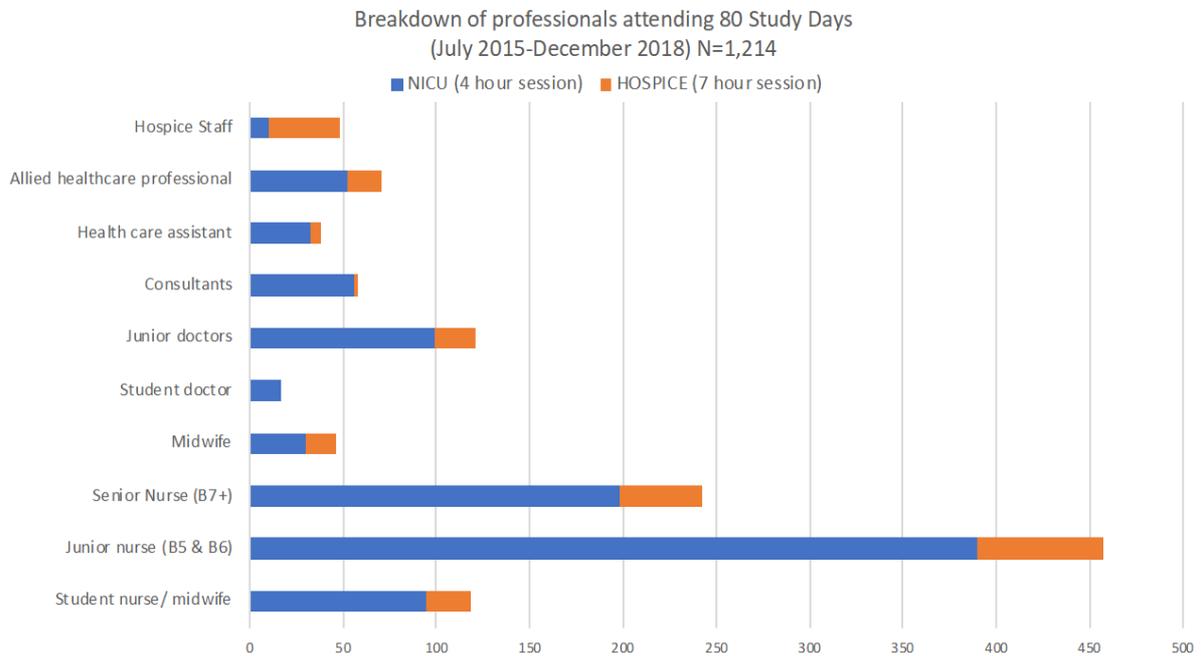
<b>0900 - 0945</b>	<b>Practical guidance for the management of palliative care on neonatal units</b> <a href="#">Alex Mancini, Pan London Lead Nurse Neonatal Palliative Care</a>
<b>0945 – 1015</b>	<b>Antenatal &amp; Neonatal support</b> <a href="#">Tara Kerr-Elliott, CNS Palliative Care/PE Louis Dundas Centre</a>
<b>1015 – 1100</b>	<b>Referrals and Resources</b> <a href="#">Richard House Hospice Care</a> <a href="#">Haven House Hospice</a>
<b>1100 – 1115</b>	<b>Coffee Break</b>
<b>1115- 1215</b>	<b>Support for families</b> <a href="#">Rainbow Trust Children's Charity</a> <a href="#">Remember My Baby</a>
<b>1215 – 1300</b>	<b>Workshop and Lunch</b>

In all, 88 Study Days were delivered from 2015 to 2018, involving over 1,330 participants (around 15 people per session, on average). The chart below provides a breakdown of the professionals attending the training:

- Nearly 60 per cent were nurses (as the key target audience), with midwives and student nurses/midwives accounting for a further 10 per cent
- 15 per cent were doctors, including nearly 60 consultants and over 120 junior doctors.

<sup>43</sup> Since 2015, nurses and midwives must 'revalidate' every 3 years to renew their registration with the Nursing and Midwifery Council, a process that includes a minimum number of CPD hours.

In addition, several one-hour training sessions were organised for neonatal consultants, at the request of hospital trusts (not included in the data shown below).



Notes: Professional data not available for 8 study days (5 hospice, 3 NICU) attended by around 120 participants. **Junior nurses** include community and paediatric nurses. **Senior nurses** are band 7 or above, including matrons, clinical nurse specialists, advanced neonatal nurse practitioner and practice development nurses. **Junior doctors** include registrars and senior house officers. **Allied healthcare professionals** include therapists (e.g. occupational, physio, speech & language), chaplains and psychologists.

The Evidence Supplement: Annex B reports on outcomes from the Study Days, based on analysis of over 900 questionnaires completed by participants.

The Pan London Lead Nurse was also a guest lecturer throughout the duration of the project, teaching on neonatal palliative care to undergraduate and postgraduate students in several of London’s universities (King’s College London, Kingston, London Southbank and Greenwich universities), helping to educate the next generation of doctors and nurses.

### 3.2 Raising awareness and influencing change

*“Being accessible, being visible and maintaining relationships which can be very fragile in an ever-changing workforce – neonatal, maternity, paediatrics. It’s really important that those relationships are fostered, nurtured and maintained and that takes a lot of time, more time than I ever anticipated. It takes you further afield than just the London region - nationally and internationally.”* Alex Mancini, Pan London Lead Nurse for Neonatal Palliative Care

A key role of the Pan London Lead Nurse has been to raise awareness of the value of palliative care approaches within neonatal units, and to promote multi-disciplinary working between neonatal and palliative care teams, as well as with other hospital and community services involved in the care of complex babies and their families. In other words: to provide system leadership and promote cultural change across the London Neonatal ODN.

A significant amount of Alex Mancini's time was therefore invested in developing relationships with key individuals and networks in the London region. This was most important in the early stages of the project, reaching out to every neonatal unit and children's hospice service, including some who were initially sceptical.

In addition to delivering Study Days which brought together a wide range of professionals for shared learning, this involved regularly attending network meetings, including the London Neonatal ODN, Children's Hospices Across London (CHAL) and the London Children's Palliative Care Network (LCPCN), as well as speaking at national and international conferences.

Working in close partnership with the London Neonatal ODN was particularly important. The Pan London Lead Nurse benefited from the robust advice and support of key colleagues in the ODN, including the Network Director, the Clinical Director, and the Lead Nurse, and considered their involvement critical to the successful delivery of this project.

### 3.3 Professional advice and support

A third strand of the Pan London Lead Nurse's role has been to offer professional advice and support, as a respected clinician and former matron with over 25 years' experience in neonatal palliative care. On a day-to-day basis, healthcare professionals across the London Neonatal ODN have been able to seek her advice and support.

*"We use Alex as a resource a lot - her guideline<sup>44</sup>, we phone her up... It's nice having that person who you know knows everything!"* Practice Development Nurse, Level 2 unit

More broadly, she advised on a wide variety of resources to support the delivery of high quality neonatal palliative care, as well as co-authoring several books and articles. These are listed below in Box 1 and include:

- A section of the London Neonatal ODN website dedicated to complex and palliative care babies, with many practical resources available to download
- Influential national guidance, including a practical guideline for neonatal palliative care (used in around one third of London's neonatal units<sup>45</sup> and many neonatal units elsewhere), guidelines on perinatal palliative care, end of life and bereavement care
- The Royal College of Nursing's Career, Education and Competence Framework for Neonatal Nursing in the UK (embedding palliative care) and an online training module on perinatal palliative care for the Royal College of Midwives and the ICPCN (International Children's Palliative Care Network).

#### Box 1: Resources developed

##### London resources

Resource section on complex and palliative care babies on London Neonatal ODN website

[www.londonneonatalnetwork.org.uk](http://www.londonneonatalnetwork.org.uk)

CHAL (Children's Hospices Across London) co-produced parent information leaflet

<sup>44</sup> Mancini A., Uthaya A., Beardsley C., Wood D. & Modi N. (Feb 2014) *Practical guidance for the management of palliative care on neonatal units*, RCPCH and Chelsea & Westminster Hospital NHS Foundation Trust

<sup>45</sup> Ibid. Mentioned by 9/27 units visited in the audit conducted for this evaluation in Summer 2019. See Annex C, Standard 3.

DVD of parent stories with CBUK to share during training sessions

### **National guidance and guidelines**

Mancini A, Uthaya S, Beardsley C, Wood D and Modi N (2014) *Practical guidance for the management of palliative care on neonatal units*. Chelsea & Westminster Hospital NHS Foundation Trust RCPCH. London.

NICE (2016) guideline '*End of Life Care for Infants, Children and Young people*' working group

Sands *Pregnancy loss and the death of a baby: Guidelines for professionals* (2016) 4<sup>th</sup> Edition

Together for Short Lives '*A Perinatal Pathway*', working group member (2017)

National Bereavement Care Pathway - steering group member and education and training (2017-19)

### **Education and training (national and international)**

RCN Royal College of Nursing (2014) *Career, education and competence framework for neonatal nursing in the UK*. RCN Guidance.

*Perinatal Palliative Care* online training module, published on ICPCN (International Children's Palliative Care Network) and RCM (Royal College of Midwives) websites.

### **Books and articles**

Editorial on *Neonatal palliative care: Together we can optimise support for infants and their families to live life* in the Journal of Neonatal Nursing (2017) 23, 47-48

Co-authored chapter in French textbook on Perinatal Palliative Care. *Livre Demarche (2017) La Démarche Palliative en Médecine Périnatale*

World Health Organisation (2018) '*Palliative Care and Symptom relief in Paediatrics*' (provided advice)

Co-authored chapter on *Communication and Psychosocial Issues within Neonatal Palliative Care* in Lloyd-Williams M. (2<sup>nd</sup> edition, 2018) '*Psychosocial Issues in Palliative Care: A community-based approach for life-limiting illness*' Oxford Scholarship Online

Mancini A., Price J. & Kerr-Elliott T. (2020) *Neonatal Palliative Care for Nurses*. First Edition Springer Nature. Switzerland. (Lead editor, co-authored 2 chapters).

Co- authored chapter on *Perinatal and Neonatal Palliative Care* in *Children's Palliative Care: An International Case-Based Manual* (2020). First Edition Springer Nature. Switzerland.

The Pan London Lead Nurse also played an advisory role on a wide variety of working groups, committees, and journals, including (current at the time of writing, unless stated):

- Clinical Ethics Advisory Group (St Thomas's, London)
- All Party Parliamentary Group (APPG) on Baby Loss
- Neonatal Nurses Association representative on the National Board for Neonatal & Paediatric Organ Donation
- Royal College of Nursing (RCN) Infant, Children & Young People's Palliative Care Forum
- Reviewer for Journal of Neonatal Nursing and BMJ professional journals
- Children's Palliative Care forum – Together for Short Lives
- Invited member of the ICPCN Scientific Committee (2017).

## **4. Professional skills and experience**

A core aim of the project was to develop a 'blueprint' which other Neonatal ODNs could draw on in extending neonatal palliative care in their own regions. With this in mind, the Pan London Lead Nurse was asked to reflect on the skills and experience needed to carry out her role effectively. Her

suggestions were triangulated with feedback from the expert stakeholders interviewed for this evaluation. Priorities to emerge were:

1. Extensive experience in a senior nurse leadership role, crossing professional boundaries (neonatal and palliative care), providing professional credibility and ready access to a wide network of supportive contacts.
2. Highly developed communication skills, or, in her own words, communication *“in a way that you’re respectful of colleagues, of people’s opinions, of their belief and where they’ve come from.”*
3. Ability to manage and nurture relationships with a wide range of stakeholders – a constant requirement!
4. Leadership and influencing skills, together with a passion for neonatal palliative care. This is an emerging specialism, so there is a need to win both hearts and minds. A neonatal consultant summarised the Pan London Lead Nurse’s approach as: *“Effective change leadership... developed consultatively, started where people were at, developing skills in a non-critical way, getting people’s input.”*

It was striking, in conducting the stakeholder interviews, how highly respected the Pan London Lead Nurse is among professionals in neonatal and palliative care, nurses, consultants and senior leaders alike, reflecting her long-standing professional experience and the role she has played, among others, in helping to pioneer the development of neonatal palliative care in this country and abroad. It is likely that this too contributed to her ability to mobilise change across such a large and diverse neonatal network.

### Administrative support

Delivering a programme of change across a large area required active communication, extensive travel, the organisation and delivery of multiple study days, as well as data inputting and analysis to track outcomes. The Pan London Lead Nurse benefitted from some administrative support (0.5 FTE), but it proved difficult to find the right skill mix, combining elements of PA support with data-inputting and analysis. An inability to fill this role continuously resulted in additional demands on the Lead Nurse’s time and some difficulties in pulling together the evidence for this evaluation, towards the end of this project.

## 5. Monitoring and evaluation

A robust evaluation framework was developed, drawing on the expertise of Advisory Board members, and much effort was invested in monitoring Study Day outcomes throughout the project. In June 2017, a structured focus group of lead nurses for neonatal palliative care from across the London Neonatal ODN was held to review progress to date, and to identify priorities for improvement.

Additional evidence-gathering was undertaken in the final year of the project for the independent evaluation which forms the basis of this report, including an audit of all 29 neonatal units involved in the project, a data request to London’s 12 palliative care teams, and semi-structured interviews with expert stakeholders. Outcomes are reported on in Chapter 3, with detailed analysis of provided in the Evidence Supplement: Annexes B and C.

The experience of conducting the independent evaluation will inform the development of a practical evaluation toolkit to support implementation in other regions.

## 6. Governance

Key lines of accountability for the Pan London Lead Nurse involved reporting to:

- The project Advisory Board
- The Director of Nursing at Chelsea and Westminster Hospital NHS Foundation Trust.

The Lead Nurse retained some clinical responsibilities at the host Trust, advising and supporting the Neonatal Palliative Care Clinical Nurse Specialist who replaced her, training neonatal and paediatric staff, and linking with adult palliative and end of life care services. She met regularly with the Director of Nursing for professional appraisal and development.

The Advisory Board played an active role in steering the project, bringing a wealth of expertise, including:

- A consultant in paediatric palliative care
- Two neonatal consultants (professors of neonatal medicine)
- The Professorial Chair in Palliative Care for Children and Young People at UCL Great Ormond Street Institute of Child Health
- A neonatal nurse academic and a neonatal lead nurse
- A psychotherapist specialising in neonatal bereavement (former Director of Training at Child Bereavement UK)
- Representatives from CHAL and Together for Short Lives.

## 7. Sustainability

One aspect of the original proposal which was not able to be taken forward was the intention to develop a specialist neonatal palliative care nurse in each of the three clinical networks within the London Neonatal ODN. They were proposed to take on much of the Pan London Lead Nurse's role, working within their own locality: teaching, promoting joint working between neonatal and palliative care services, and supporting and advising colleagues. As well as sharing a heavy workload, this would be valuable in helping to ensure sustainability, as; in the words of the Pan London Lead Nurse: *"I'm acutely aware that I'm just one person!"*

Staffing shortfalls in London's neonatal units (referenced earlier in this chapter) proved too much of a barrier for senior neonatal nurses to be released to work alongside the Pan London Lead Nurse and develop into such roles. As a result, when the Pan London Lead Nurse had to take several months off in 2019 due to bereavement and planned surgery, this necessitated a pause in the project's delivery.

The interviews conducted for this evaluation with stakeholders in London indicate that there is demand for such roles, and more broadly, to find a way of linking up key professionals across the London Neonatal ODN to support the continued development of neonatal palliative care across the region. This is discussed further in Chapter 3 and is reflected in the report's recommendations.

As previously noted, it was intended that the model developed in London should provide a practical blueprint for developing neonatal palliative care, which could be adapted and implemented in other regions.

Since this evaluation report was written, the COVID-19 pandemic necessitated a rethink of the delivery model. The Pan London Lead Nurse adapted the education and training programme to be delivered virtually, as well as providing emotional support for neonatal nurses working under unprecedented pressure during the pandemic. This is described in more detail at the end of Chapter 3, together with the recommendations flowing from the independent evaluation.

## Chapter 3: Learning from the Pan London Neonatal Palliative Care project

1. Evidence base for this chapter
2. Key finding from the evaluation: Impact and influence
3. Barriers to change
4. Potential for improvement

### 1. Evidence base for this chapter

The analysis presented in the chapter draws together a wide range of evidence, including:

- Over 900 questionnaires completed before and after Study Days, from 2015 to 2018;
- A short online survey to explore impact several months after the training, completed by 32 Study Day participants between October 2017 and July 2018;
- An interim evaluation conducted in June 2017, involving a structured focus group of eight lead nurses for neonatal palliative care from across the London Neonatal ODN;
- A detailed audit of neonatal palliative care provision across the London Neonatal ODN in Summer 2019, which was analysed thematically;
- Retrospective data on ante- and post-natal referrals from specialist and palliative care services in London, with some data provided by half of such services;
- Semi-structured interviews with ten expert stakeholders (nurses and consultants in neonatal and palliative care, hospice staff, nurse educators, and senior London Neonatal ODN staff) to explore the impact and influence of the project, and to seek insights as regards sustainability and replicability of the model to other regions.

Detailed analysis of the evidence on Study Day outcomes and the audit findings are provided in the Evidence Supplement: Annexes B and C respectively.

Although there are some gaps in the evidence, for example, the lack of a baseline against which to assess progress, every strand of evidence was consistent in demonstrating the very positive impact and influence of the Pan London Lead Nurse for Neonatal Palliative Care.

### 2. Key findings from the evaluation: Impact and influence

#### 2.1 Improved equity, care and choice for families

*“This experience defines the rest of their life. If you manage to do this well, that’s a gift that goes on for years.”* Neonatal consultant

Two of the top strengths of the Pan London Neonatal Palliative Care Project, identified in the interim evaluation focus group (June 2017), were:

*“Improved provision of choice for families with end of life care decisions, such as transfer to a hospice, referrals to a hospice for family support, first experience of exploring organ donation.”*

*“Improved parent and family experience, e.g. reducing stress for the family and empowering them with information, knowledge and skills to make informed decisions.”*

Stakeholders interviewed for this evaluation in Autumn 2019 consistently highlighted the positive impact of the Study Days on the care provided in neonatal units:

*"It really does influence the care families are given."* Nurse educator

*"Staff really value the training and it really does change their perspective on caring for complex babies and trying to get them discharged sooner... That's been key and I don't think it would've happened otherwise."* Senior nurse in strategic role

The Study Days were perceived to have 'filled a gap' in nurse education in particular, where palliative care was previously a minor part of bereavement education and training. As a neonatal consultant explained:

*"It is an area people struggle with – the emotional element and understanding the breadth of palliative care and the complex care planning part of it."*

Nurses in particular were "empowered" by the training and "much more able to talk about it [palliative care] now." Palliative care consultant

*"It has enabled people to think on different levels about what they can do themselves."* Palliative care nurse

Analysis of the post-training questionnaires and the online follow-up survey also indicated the positive impact of the Study Days on the care and choices offered to families.

The post-training questionnaire (final version 2017/18) asked how far the Study Day contributed to 'Improved understanding of what services and resources are available to families and how to access them, enabling equity of choice for families.' 91% of respondents (N=128) answered 'completely', making this the joint highest rated learning outcome, alongside, 'improved understanding of the principles in neonatal palliative care.'

The online follow-up survey asked if people who had attended the training had 'increased confidence in caring for babies with complex and palliative needs and their families, following the training day.' 26 out of 28 respondents answered yes, with 24 providing further information. The most common reason for feeling more confident (10 responses) was improved knowledge and understanding of resources and services to support families, for example: *"More aware of what is available and feel more confident discussing options with parents."*

One of the stakeholders interviewed (a Practice Development Nurse in a Level 2 unit) believed that the Study Days had contributed to *"More and better parental engagement...It used to be telling them what would happen, rather than giving them choices of where they want to go."* She also pointed out that families now experience a more consistent approach when complex babies transfer between neonatal units, because staff in every unit have benefitted from the same Study Days and have access to the same range of advice, information, and resources on neonatal palliative care.

## 2.2 Embedding palliative care approaches in neonatal units: new ways of working and a cultural shift?

Stakeholders interviewed for this evaluation were asked about specific changes in their unit or service, influenced by this project. While these may not be representative, they indicate a significant influence. For example, changes reported by a senior nurse in a Level 2 unit include:

- Allocating a sister to lead on palliative care
- More forward planning and multi-disciplinary working e.g. consultants meet families with an antenatal diagnosis to discuss what may happen, choices, next steps. *“We’re better prepared, we communicate better, plans are in place and shared - everyone knows what the plan is.”*
- Converting rooms off the unit for extubation and end of life care, in partnership with the bereavement midwives
- Developing their knowledge of organ donation and the offer of this to parents, which was coming through anyway, but was included in the Study Days.

An audit of neonatal units across the London Neonatal ODN in Summer 2019 provided a snapshot of how far neonatal units in London have taken on board palliative care approaches. Findings are reported in full in the Evidence Supplement: Annex C, but in brief, more than two-thirds of London’s neonatal units now:

- Have a named lead for palliative care
- Use a palliative care guideline or framework to support staff in delivering high quality care
- Have a regular multi-disciplinary meeting where complex babies who may be eligible for palliative care are identified
- Have robust links with community palliative care services
- Offer regular education and training on palliative care
- Offer memory-making opportunities
- Have a private room for families to spend time with their baby, nearing end of life or after death.

As may be expected (given resource limitations and caring for fewer babies with complex needs), the audit shows that palliative care approaches are less well embedded in Level 1 units than in Level 3 units, with much variation between the Level 2 units.

Study Day participants also reported a wide variety of ways in which they had put their knowledge into practice in their neonatal units since the training. Key themes to emerge from the online follow-up survey and from Study Day questionnaires completed by participants who had previously attended the training were:

- Improved multi-disciplinary working
- Developing pathways and/or guidelines
- Developing practical resources, sharing learning with colleagues
- Improving psychological support.

These are considered in brief below, triangulated with wider evidence from the evaluation.

### Multi-disciplinary working

27 of the 29 people responding to the online follow-up survey indicated that they had worked with or referred a family to a range of palliative care services since the Study Day (the other two answered ‘n/a’ in their current role). One commented:

*“The Study Day highlighted how we need to network more closely together to get the care right for the babies and their families.”*

Consistent with this, 'Improved understanding of the collaboration across local services for consistent high quality care' was a highly-rated learning outcome in the 2017-18 post-training questionnaires, with 88% of respondents feeling that the training achieved this 'completely'.

Stakeholders interviewed suggested that the Study Days helped to strengthen links between neonatal and palliative care services, especially children's hospices, as well as facilitating better communication between doctors and nurses caring for complex babies.

*"She's done an amazing job in bridging the two worlds (of neonatal and palliative care)." Palliative care nurse*

Improvements in multi-disciplinary working were also identified as one of the top strengths of the project in the interim evaluation carried out in June 2017, specifically: *"Networking within hospital and external services - Midwifery & Paediatrics, Rainbow Trust Charitable organisations, Siblings group."*

### Developing pathways and/or guidelines

The follow-up online survey asked whether people who had attended a Study Day had embedded aspects of the training into their routine neonatal care. Nearly one-third (10 out of 32 respondents) indicated that the "development of local guidelines or pathways" was the option implemented in their neonatal unit (only one option could be selected).

The audit showed that the practical guideline developed by the Pan London Lead Nurse with colleagues at Chelsea and Westminster Hospital NHS Foundation Trust in collaboration with the RCPCH is now used in around one-third of London's neonatal units.<sup>46</sup>

*"Alex's work on palliative care pathway, first developed at Chelsea and Westminster, has increased knowledge and awareness, probably helped to get some babies out of NICU sooner and on to a palliative care pathway."* Neonatal nurse in a strategic role

### Developing practical resources, sharing learning

34 Study Day participants had attended a similar training session before, 19 of whom shared details on how their practice had since changed. Five said that they had shared information with colleagues and/or developed practical resources, for example:

*Will make our services better as currently re-doing our folders, forms, memory boxes  
Support to teams/ network whenever an opportunity to disseminate information through different networks/ clinical presentation.*

Consistent with this, the audit revealed many positive examples of thoughtful approaches (e.g. memory boxes and photography, comfortable rooms for families to spend time with a baby at end of life, cold cots) in all levels of unit. A hospice nurse interviewed for this evaluation observed: *"The way things are managed on neonatal units and in maternity - memory making, cuddle cots, giving families more time - all that's improved."*

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<sup>46</sup> Explicitly mentioned in 9/27 units visited in the audit. Mancini A., Uthaya A., Beardsley C., Wood D. & Modi N. (Feb 2014) *Practical guidance for the management of palliative care on neonatal units*, RCPCH and Chelsea & Westminster Hospital NHS Foundation Trust

## Psychological support

The same post-training survey question indicated that the Study Days prompted some units to look at how they could improve psychological support for parents and staff. Four (of 19 respondents to this question) mentioned this explicitly:

*We now have a unit psychotherapist*

*Understanding compassion fatigue*

*We have asked for a copy of the debriefing framework so that we can incorporate it into our practice*

*Using the palliative team to help to direct pre-debrief discussion with staff was beneficial to all involved, it also helped to inform our practice on the unit.*

However, access to psychological support emerged as an area for development in around 20 per cent (support for staff) and 25 per cent (support for parents) of neonatal units in London, in the audit conducted for this evaluation during Summer 2019.<sup>47</sup> Similar concerns have been raised in recent research.<sup>48</sup>

## A cultural shift?

Several of the stakeholders interviewed suggested that the positive changes influenced by this project amounted to a cultural shift towards embedding palliative care approaches in London's neonatal units.

*"People no longer look at me strangely when I talk about neonatal palliative care. People didn't used to put those two things together in one sentence... It's become a standard part of what we do... because of Alex's guidance, the training and all the long hours she's put in."* Neonatal consultant

*"She's massively raised the profile of neonatal palliative care ... promoting learning between those 2 worlds ... It's now recognised in its own right, not as an add-on. People recognise the need for this."* Palliative care nurse

Nonetheless, it is important to note that much variation persists between neonatal units, both in practice (as shown by the audit, see Evidence Supplement: Annex C) and in the attitudes of professionals involved in the care of babies with palliative care needs. This is discussed further in the next section.

## 2.3 Closer working with children's hospice and paediatric palliative care services

*"It has changed. Four years ago, it was very unusual for a child (in her area) to go home for end of life care or to a hospice, even unheard of."* Hospice nurse

All the stakeholders interviewed for this evaluation highlighted strengthened links with children's hospice and other palliative care services as a positive outcome from this project. This was supported by the audit findings, which indicated that hospice and specialist paediatric palliative care

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<sup>47</sup> See Evidence Supplement, Annex C, Standard 10: Staff support.

<sup>48</sup> For example <https://www.bliss.org.uk/news/bliss-releases-new-research-on-mental-health>

teams are regularly consulted and involved by many of London’s neonatal units. Their involvement was most often mentioned with respect to:<sup>49</sup>

- Supporting parents’ choices and transitions to home or hospice (hospices mentioned by 22 units, specialist palliative care teams by 9 units)
- Providing ‘hospice at home’ services (11 units)
- Using hospice or specialist palliative care team plans, as appropriate (10 units)
- Participation in multi-disciplinary team meetings to discuss eligible babies (5 units)
- End of life care (19 units mentioned transfers to hospice or home)
- Sibling support (from children’s hospices, 13 units)
- Counselling, especially post-bereavement (6 units)
- Hosting and contributing to Study Days and hospice visits for neonatal staff.

### Referrals to palliative care services

Analysis of the Study Day questionnaires completed before and after training provided clear evidence of increased confidence in making referrals to palliative care services, including children’s hospices, hospital palliative care teams, community-based palliative care teams, and community children’s nursing. Of those who attended the training in 2015 and 2016:

- Those feeling ‘not confident’ in making referrals to palliative care services fell by 42 percentage points, from one in every two participants (52%) pre-training, to one-in-ten (10%) post-training
- Those feeling ‘confident’ increased by 40 percentage points, from around one quarter (27%) of participants pre-training, to two-thirds (67%) post-training
- Those feeling ‘very confident’ increased by 11 percentage points, from 4% pre-training to 15% post-training.

#### ***How confident do you feel making a referral to palliative care services?***

RESPONSES	NOT CONFIDENT	CONFIDENT	VERY CONFIDENT	N/A
Pre-training (N=265)	52%	27%	4%	17%
Post-training (N=330)	10%	67%	15%	8%

*Survey responses from 24 Study Days in 2015-2016.*

The question format changed in early 2017 (making valid comparisons difficult); nonetheless more than four-fifths of Study Day participants (83% in 2017) reported that they felt confident about making a referral to palliative care services having completed the training, similar to the positive outcomes reported during 2015-16 (82% feeling confident or very confident).

### Referrals received by palliative care services

In Summer 2019, retrospective data on neonatal and antenatal referrals were requested from all six children’s hospice services in London as well as the six specialist and community palliative care teams<sup>50</sup>. Half were able to provide some data, including four hospice services, one community

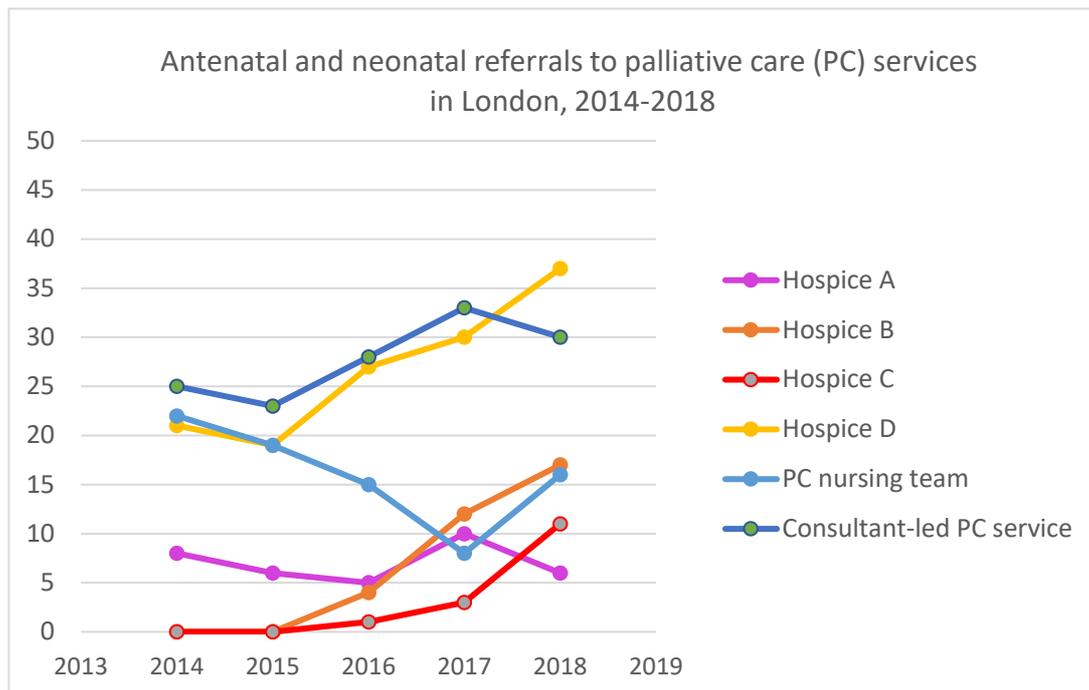
<sup>49</sup> Audit findings described in detail in the Evidence Supplement to this report, Annex C.

<sup>50</sup> The opening section of Annex C provides an overview of neonatal and palliative care services in London.

nursing team, and one specialist consultant-led team. Data quality was variable, so some caution is warranted.

The data reported by these six palliative care services indicate an overall increase in antenatal and neonatal referrals from 2014 to 2018 for most of these teams, from a low base (see chart). The number of referrals received by these services appears low compared to potential need. As reported in Chapter 1, around 800 babies per year admitted to neonatal units in London may have palliative care needs.<sup>51</sup>

The palliative care services data also indicate a wide variation in terms of how early referrals are made, where they come from (neonatal units, maternity departments, community nursing teams, specialist care services), as well as in the range of services provided by children’s hospices across London.



Senior staff in two children’s hospices interviewed for this evaluation reported that they had worked hard to strengthen links with neonatal units, with some progress, but as one noted, “*there is still a long way to go.*”

They felt they would be able to support families better if referrals were made sooner, even antenatally. They were concerned that some neonatal consultants only look to involve hospices in end of life and bereavement care, and that this may influence some families to turn down the offer of hospice support. Similar views were articulated by a consultant in paediatric palliative medicine, who regretted that neonatal colleagues do not involve the palliative care team earlier or give more recognition to the breadth of support they offer. This is consistent with recent research in respect of both hospice and paediatric palliative care services.<sup>52</sup> It was also echoed by one of the consultant

<sup>51</sup> Data extracted for this evaluation suggest that around 7 per cent of babies in London’s neonatal units are eligible for palliative care (around 800 babies per annum). Annex A provides a detailed report on the data.

<sup>52</sup> Price J.E. & Mendizabal-Espinosa R.M. (2019) *Juggling amidst complexity – Hospice staff’s experience of providing palliative care for infants referred from a neonatal unit*, Journal of Neonatal Nursing; and Twamley K., Craig F. et al (2014)

neonatologists interviewed for this evaluation, who acknowledged the persistence of “a lack of recognition” of what palliative care services do and felt that “we could work together better.”

## 2.4 Education and training outcomes

The rolling programme of Study Days delivered in neonatal units and hospices across the London Neonatal ODN was central to this initiative. In total, 88 Study Days were delivered to over 1,330 participants from 2015 to 2018. Feedback from stakeholders was very positive and their continuous delivery across such a large, diverse network was seen as a major achievement.

The Study Days were rated highly by more than four-fifths of participants:

- 89% of participants on hospital-based Study Days between 2015-18 (N=463) said the training met their expectations ‘completely’, with the remainder (11%) answering ‘somewhat’.
- 80% of participants on the hospital-based Study Days from 2015-2016 (N=335) said the learning sessions met their learning needs ‘completely’, and 85% on the Study Days in 2017-18 (N=128), with 19% and 15% respectively answering ‘somewhat’.
- On the hospice-based Study Days where a standard survey was used (N=107), 93% of learning sessions were rated ‘excellent’ or ‘good’, with 7% rated ‘average’ or ‘fair’.

Study days were “incredibly popular amongst staff”, according to a neonatal consultant, and many requests for their continued delivery were made in the stakeholder interviews, with a variety of suggestions for how they could be further developed, including more parent involvement and online refresher modules. Progress has already been made in implementing these ideas.<sup>53</sup>

Study Day questionnaires also explored priorities for future education and training. Top priorities to emerge, which will be taken into account in the next phase of the project, include:

- Sensitive discussions with parents (around a difficult prognosis and options for care)
- Organ donation
- Knowledge of hospice services and referrals
- End of life care
- Caring for a baby who has died on the unit and their family
- More parents’ experiences and more case studies for discussion.

## Wider factors influencing change

A variety of external factors are also likely to have influenced the development of neonatal palliative care in London, in parallel with this project.

Firstly, many children’s palliative care services (hospices, specialist, and community teams) have developed over the past decade and beyond, and in more recent years, extended their role into neonatal care. They have played an important role in supporting the development of neonatal palliative care in London.

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*Underlying barriers to referral to paediatric palliative care services: Knowledge and attitudes of health care professionals in a paediatric tertiary care centre in the United Kingdom, Journal of Child Health Care*

<sup>53</sup> The Pan London Lead Nurse has recorded a DVD of family case studies with Child Bereavement UK to use in training healthcare professionals, and developed shorter, online training sessions in context of the COVID-19 pandemic.

Secondly, several high-profile cases in the media, highlighting the agonising decision-making around compassionate care for babies with life-limiting conditions, have both “made people more aware and more wary of neonatal palliative care.” (Palliative care nurse)

Third, to quote a palliative care nurse interviewed for this evaluation: “Neonatal care is more complex in every way”. As noted in Chapter 1, advances in technology and medicine enable the survival of many babies who, in past decades, would have died. This initiative was developed in response to the needs of these babies and their families, and with recent guidance advising in specific circumstances, the consideration of life-sustaining treatment for babies born at 22 weeks gestation<sup>54</sup>, it remains as relevant as ever.

### 3. Barriers to change

#### 3.1 Workforce

As noted in Chapter 2, there are significant neonatal workforce challenges in London, particularly in nurse recruitment. Stakeholders felt that this may have impeded the roll-out of this programme – making it harder for staff to be released to attend Study Days and for neonatal units to allocate dedicated senior nurse time to lead on palliative care or to invest in developing new ways of working, resources and facilities for families.

This also meant that one of the early ambitions of the programme: to develop a specialist neonatal palliative care nurse in each of London’s three clinical networks, was not taken forward. Several stakeholders suggested developing this sort of approach in the next phase of this project, which is reflected in the report’s recommendations.

#### 3.2 Resources

Resources were highlighted by stakeholders as an important barrier to progress, particularly with respect to children’s hospice services and community nursing, both services which enable complex babies to be discharged from neonatal care sooner, to go home, or to a children’s hospice. Hospice directors were clear that resources represent a significant challenge in extending their services further into neonatal care, reporting that some services (e.g. use of the bereavement suite, if the baby has already died) are not currently funded. This is likely to vary locally. Hospices have discretion over how to invest their voluntary funding, so this may also reflect their own strategic priorities.<sup>55</sup>

One of the palliative care nurses interviewed for this evaluation was concerned that hospice services are being called on “to plug gaps in children’s community nursing” e.g. by providing weekend cover. The audit evidence (see Annex C) is consistent with this perception, indicating that hospices are also improving access to bereavement counselling and sibling support, as well as providing more generous, holistic packages of ‘step-down care’ for babies discharged home with complex healthcare needs (see Charlie’s story, Chapter 1).

Conversely, resource challenges could be seen as a ‘lever for change’ in the commissioning and delivery of neonatal critical care. As one neonatal consultant acknowledged: “Babies used to get

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<sup>54</sup> BAPM (2019) *Perinatal management of extreme preterm birth before 27 weeks of gestation: A framework for practice.*

<sup>55</sup> *Forget Me Not* children’s hospice in Huddersfield has invested in developing support for families with babies diagnosed antenatally or after birth <https://www.forgetmenotchild.co.uk/help-for-families/how-we-help/our-services/pregnancy-birth>

*stuck in neonatal intensive care for a long time.*” Supporting families to make choices about their baby’s care - to go home, to a hospice, to a local hospital, or if the prognosis is very poor, in the difficult decision to withdraw life-sustaining treatment - is consistent with improved outcomes for families and more efficient working in neonatal units. For this reason, participation in this project was advocated by the London Neonatal ODN as a requirement of the NHS England “*Improving Value in Specialised Services*” scheme.<sup>56</sup> This could also help to drive change when this initiative is extended in other regions.

### 3.3 Culture and ways of working

Although this evaluation has noted much progress in joint working between neonatal units and children’s palliative care services, differences in culture and ways of working were widely acknowledged as barriers to change. This was reflected in the views of stakeholders on both sides interviewed for this evaluation, as described earlier in this chapter<sup>57</sup>, and is consistent with academic research.<sup>58</sup>

This evaluation found clear evidence of the benefits of bringing professionals from neonatal and palliative care services together for shared education and training (through the Study Days), consistent with the evaluation of the pilot programme that preceded this project.<sup>59</sup> Nurse rotation posts, piloted in two of London’s neonatal units in partnership with local hospice services, may also offer a valuable way to strengthen joint working to support improvements in the care of complex babies and their families.<sup>60</sup>

## 4. Potential for improvement

### 4.1 ‘Empowering’ Level 1 and 2 units

The audit pointed to much progress in embedding palliative care approaches in neonatal units across London, but with great variation in Level 2 (LNU) and Level 1 (SCBU) units particularly. Where units were known to have a consultant or a senior nurse with a special interest in palliative care, they tended to meet more of the audit standards (but this could not be analysed robustly<sup>61</sup>). On some standards, such as having a dedicated room for sensitive conversations and ready access to a psychologist, resource constraints are likely to have played a part.

Two neonatal consultants in Level 3 units (NICUs) interviewed separately for this evaluation wondered what more could be done to empower local hospitals to embrace neonatal palliative care more fully. They both described a trend for babies nearing the end of their life to be transferred to Level 3 units<sup>62</sup>, which may be appropriate in some circumstances, but can mean that families are separated and lose precious time with their baby. This is an issue the London Neonatal ODN may

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<sup>56</sup> <https://www.england.nhs.uk/commissioning/spec-services/improving-value/>

<sup>57</sup> Chapter 3, section 2.3 Closer working with children’s hospice and paediatric palliative care services

<sup>58</sup> Price J.E. & Mendizabal-Espinosa R.M. (2019) *Juggling amidst complexity – Hospice staff’s experience of providing palliative care for infants referred from a neonatal unit*, Journal of Neonatal Nursing; and Twamley K., Craig F. et al (2014) *Underlying barriers to referral to paediatric palliative care services: Knowledge and attitudes of health care professionals in a paediatric tertiary care centre in the United Kingdom*, Journal of Child Health Care

<sup>59</sup> Twamley K, Kelly P et al (2012), *Palliative care education in neonatal units: impact on knowledge and attitudes*, BMJ Supportive & Palliative Care

<sup>60</sup> Supported by a grant from the Burdett Trust <https://chal.org.uk/burdette/>

<sup>61</sup> This information was not collected in the audit, so could not be analysed robustly.

<sup>62</sup> It should be possible to corroborate this by looking at data on neonatal deaths, but this was not within the scope of this evaluation.

wish to explore further, in line with the first objective in the Toolkit for high-quality neonatal services (DH, 2009): “that babies and their families receive the highest quality of care, as close to home as possible” and more recently, the vision for neonatal services set out in Neonatal Critical Care Transformation Review:

“A seamless, responsive and multidisciplinary service built around the needs of new-born babies and the involvement of families in their care. High quality neonatal care will be networked together across England, to improve outcomes for all families, provide safe expert care as close to their home as possible, and keep mother and baby together while they need care.”<sup>63</sup>

## 4.2 Listening to families

The audit found very little evidence of neonatal units routinely seeking formal feedback to inform their practice from families with babies with palliative care needs.<sup>64</sup> A maternity bereavement feedback tool<sup>65</sup> exists, but there is a gap in learning from the wider group of families whose infant is discharged after weeks or months in neonatal care.

Two stakeholders suggested that parents should be more actively involved in the delivery of this project, either as speakers on Study Days, or in an advisory capacity. A DVD of families’ stories to use in training healthcare professionals has since been recorded and is shared during the training sessions.

## 4.3 Monitoring and evaluation

Although a robust evaluation framework was developed early in the project, there were some gaps and delays in its implementation, leading to challenges in pulling together the evidence for this evaluation. This experience will inform the development of a practical evaluation toolkit to support implementation in other regions, as per the report’s recommendations. Clear evidence of impact and outcomes will be key to ensuring sustainability.

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63 NHSE/I (Dec 2019) *Implementing the Recommendations of the Neonatal Critical Care Transformation Review*

64 See Annex C, Standard 16: Parent feedback

65 The Maternity Bereavement Experience Measure <http://www.londonscn.nhs.uk/wp-content/uploads/2017/06/mat-bereavement-mbem-062017.pdf>

## Recommendations and COVID-19 update

Recommendations from the independent evaluation were made to the project's funding partners in March 2020, shortly before the UK went into lockdown due to the COVID-19 pandemic. These are shown at the end of this chapter, grouped under three headings:

1. Consolidating on progress made in London
2. Preparing to extend the pilot to Neonatal ODNs in other regions
3. Implementing the pilot in other regions

However, a great deal has changed in the months since these recommendations were written. The COVID-19 pandemic has major implications for the delivery of neonatal critical care and of course, for the delivery of this project. The recommendations are therefore preceded by an update on COVID-19, the work of the Pan London Lead Nurse through the pandemic, and plans for the future.

### COVID-19 update (November 2020)

The COVID-19 pandemic necessitated a pause in the project and a rethink of the delivery model. Supported by an interim grant from the True Colours Trust, the Pan London Lead Nurse has provided 1:1 advice and emotional support to neonatal colleagues working under unprecedented pressure throughout the pandemic, also facilitating a weekly virtual peer support group for neonatal nurses in London.

*"The emotional distress experienced by neonatal nurses caring for babies with life-limiting conditions and supporting their families is well recognised. This has been compounded by the impact of COVID-19. Parents have restricted access to their babies, often only one parent at a time. Additionally, difficult news is shared whilst wearing full PPE. This can add to the trauma suffered by parents and to the distress experienced by neonatal nurses, who may also be worrying about their own family and financial loss. The pressures neonatal nurses are coping with in the pandemic are unprecedented and it is essential they are well supported."* Alex Mancini, Pan London Lead Nurse for Neonatal Palliative Care

The training programme was rapidly adapted to deliver virtual learning from May 2020, with:

- Weekly themed workshops for neonatal staff in London, as well as colleagues in maternity, paediatrics, hospice and palliative care teams. Staff in other regions were also invited, to build relationships in new areas.
- Monthly 'train the trainer' sessions for the 27 neonatal palliative care link nurses in London, to help ensure future sustainability.

The True Colours Trust, Chelsea and Westminster Hospital NHS Foundation Trust and its charity CW+ remain committed to this project and are in discussions with the Pan London Lead Nurse about the next phase, to consolidate on progress made in London and to extend the initiative to several other regions, using the adapted COVID-19 delivery model.

## Recommendations from the independent evaluation (March 2020)

### To consolidate on progress made in London

1. Developing a sustainability strategy should be a key priority for the Pan London Lead Nurse now, working closely with the London Neonatal ODN. This should include:
  - 1.1 Developing the next tier of Specialist Neonatal Palliative Care Nurses (at least one for each of London's three neonatal ODNs) to replicate as much as possible of the Pan London Lead Nurse's role, within their local patch.
  - 1.2 Encouraging/supporting the development of a Pan London special interest group(s) on neonatal palliative care; for example, for Practice Development Nurses, consultants, and allied health professionals.
  - 1.3 Developing a bank of useful resources for neonatal units to draw on in improving their approach to neonatal palliative care, building on those already curated on the London Neonatal ODN website. This could include facilitating the development of new resources, in partnership with others. Priorities emerging from the audit include:
    - a) Eligibility tool for use in multi-disciplinary team discussions to help identify babies sooner and more consistently
    - b) Feedback tool to learn from families' experiences of neonatal palliative care.
2. Study Days should continue on a time-limited (and possibly more targeted) basis to embed progress, with the explicit aim of developing a sustainable education and training delivery model for partners in London to take forward.

### To prepare to roll out the pilot to Neonatal ODNs in other regions

3. An influencing strategy should be developed, drawing on the experience of this pilot, to encourage national and local commissioning of neonatal palliative care. This should include:
  - a. Identifying (and perhaps piloting in London) a small number of outcomes measures (e.g. age at time of discharge from neonatal care) which are high priorities for Neonatal ODNs, Trusts and commissioners, linked to NHSE/I improvement initiatives, notably the Neonatal Critical Care Review, Getting it Right the First Time, Improving Value in Specialised Services, as well as the NHSE Paediatric Palliative & End of Life Care Programme<sup>66</sup> and the new Care Coordinator role.
  - b. Working with NDAU colleagues to develop robust regional and national estimates of the number of babies in neonatal care eligible for palliative care and to improve data recording in the Neonatal Dataset. This should involve a wide stakeholder group to agree which specific conditions fulfil BAPM categories 1-5.<sup>67</sup>
4. A practical evaluation toolkit should be developed, building on the experience of this evaluation, to support implementation in other regions.

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<sup>66</sup> [https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/06/PolRes\\_NHS-England.pdf](https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/06/PolRes_NHS-England.pdf)

<sup>67</sup> As recommended by Dr Cheryl Battersby, who kindly extracted and analysed these data for this evaluation.

## Implementation in other regions

5. A Regional Specialist Nurse should be recruited to play a leadership role in influencing the development of neonatal palliative care in selected regions, mentored and supported by the Pan London Lead Nurse.
6. Sustainability should be a clear aim from the outset, explicit in discussions with the Regional Neonatal ODN and other delivery partners, and embedded in the approach developed. This could include developing:
  - A tier of Specialist Nurses (perhaps on an area basis in large regions) to champion and support neonatal palliative care in their patch
  - Regional/area special interest group(s) to nurture and develop champions of neonatal palliative care
  - A committed approach to evaluation, using the tools developed in the London pilot, with key indicators to reflect the priorities in each region.
7. We recommend that an audit of regional provision (using the London audit tool, with some minor improvements) is conducted by the Regional Specialist Nurse at the outset, providing a baseline against which to measure progress and to inform training and development priorities. This should include structured information-gathering from children's hospice services and palliative care teams.