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Independent Evaluation of the Pan London Lead Nurse for Neonatal Palliative Care Project: Executive Summary

by Anne Pinney, Independent Researcher
November 2020

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

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.¹

Although survival rates and outcomes have improved steadily over the past 25 years², 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 of withdrawing 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.³

“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.⁴ The under-1 age group has by far the highest 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,

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

² NHSE/I (2019) *Implementing the Recommendations of the Neonatal Critical Care Transformation Review*, p.3

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

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

Imperial College London⁵, 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, 2010⁶). Many of these babies were discharged home, pointing to the need for continued support in the community.⁷

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+. In addition to supporting progress in London, it aimed to develop a 'blueprint' to 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.”⁸

Three strands of work have been involved:

- i. **Study Days** in neonatal units and children’s hospices across London, bringing together neonatal and palliative care nurses, doctors, and allied health professionals, as well as staff from maternity and paediatric services. A total of 88 Study Days were delivered during 2015-2018, reaching over 1,330 participants.
- ii. **Change leadership** by promoting palliative care principles and approaches in London’s neonatal units, sharing information and practical resources and breaking down professional boundaries between neonatal and palliative care services.
- iii. **Professional advice and support** to colleagues in London’s neonatal units, particularly on difficult cases; also advising on many influential tools and resources to support improvements in practice, in London and nationwide.

Purpose and timing of this report

An independent evaluation of the Pan London Lead Nurse for Neonatal Palliative Care 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.

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

⁶ 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*. Annex A provides the full article on the data analysis.

⁷ See Annex A, table 2. Even for babies in BAPM category 1, deemed not to survive in the long-term, 40% are discharged home. 65-70% of those babies who are likely to have impaired quality of life are discharged from neonatal care.

⁸ Memorandum of Understanding between the funding partners, October 2014.

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 2015-2018
- An audit of neonatal palliative care provision across the London Neonatal Operational Delivery Network (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, as summarised below.

Key findings from the independent evaluation

1. Improved equity, care and choice for families

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

“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:

“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.” Neonatal consultant

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

The post-training questionnaire 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 answered ‘completely’, making this the joint highest rated learning outcome alongside ‘improved understanding of the principles in neonatal palliative care.’⁹

2. New ways of working on neonatal units and a cultural shift?

An audit of every neonatal unit in the London Neonatal ODN, and two nearby units in Essex involved in the project, in Summer 2019 provides a snapshot of how far palliative care approaches have been embedded.¹⁰ More than two-thirds of London’s neonatal units:

⁹ This question was in the final version of the survey, 2017/18 (N=128). Annex B reports in detail on Study Day outcomes.

¹⁰ Annex C reports in detail on the audit of neonatal palliative care provision.

- 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, at end of life.

“The way things are managed on neonatal units and in maternity - memory making, cuddle cots, giving families more time - all that’s improved.” Hospice nurse

Study Day participants reported a wide variety of ways in which they had put their knowledge into practice in their neonatal units. Key themes to emerge from those who had previously attended the training were:

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

Several stakeholders suggested that the 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

3. Closer working with children’s hospice and paediatric palliative care services

All the stakeholders interviewed for this evaluation highlighted strengthened links with children’s hospice and paediatric palliative care teams as a positive outcome from this project. This is consistent with the audit of London’s neonatal units, which indicated that children’s hospices and palliative care teams are most often involved in:¹¹

- 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 (mentioned by 11 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, mentioned by 13 units)
- Counselling, especially post-bereavement (mentioned by 6 units).

Analysis of the questionnaires completed before and after Study Days provided clear evidence of increased confidence in making referrals to palliative care services.

However, it was also clear from each strand of evidence that variations in practice and attitudes persist. Senior staff in two children’s hospices felt that although progress had been made in strengthening links with neonatal units, *“there is still a long way to go.”* They believed they could

¹¹ Audit findings are described in detail in the Evidence Supplement to this report, Annex C.

support families more effectively if referrals were made sooner, antenatally if possible. They were concerned that some neonatal consultants tend to involve hospices only in end of life and bereavement care, and that such attitudes influence some families to turn down the offer of hospice support. Similar views were articulated by a consultant in paediatric palliative medicine, who wished that neonatal consultants would involve the palliative care team earlier and give more recognition to the breadth of support they offer. This is consistent with recent research into both children's hospice and paediatric palliative care services.¹²

Barriers to change

This project was delivered during a period of neonatal workforce challenges in London, particularly in nurse recruitment.¹³ This made it harder for neonatal units to release staff for Study Days and to allocate dedicated senior nurses time to lead on palliative care.

Resource constraints were another barrier highlighted by stakeholders, particularly for children's hospice services and community nursing – both crucial services which enable complex babies to be discharged from neonatal care sooner, if their parents wish.

However, resource challenges could also be seen as a 'lever for change' in neonatal critical care. 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.¹⁴ This could also help to drive change when this initiative is extended in other regions.

Although resource constraints meant that the London Neonatal ODN was unable to fund the project, they provided robust, invaluable, and essential support throughout, which were critical to the project's impact.

Recommendations and next steps

In light of the very positive outcomes achieved by the Pan London Lead Nurse for Neonatal Palliative Care, the independent evaluation concluded with recommendations to consolidate on progress made in London and to prepare to extend this project to Neonatal ODNs in other regions.

The COVID-19 pandemic, resulting in a national lockdown beginning in March 2020, 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 provided 1-to-1 advice and emotional support to neonatal colleagues working under unprecedented pressure through the pandemic, and facilitated a weekly virtual peer support group for neonatal nurses in London.

¹² 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

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

¹⁴ <https://www.england.nhs.uk/commissioning/spec-services/improving-value/>

She rapidly adapted the training programme 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 have also been 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.

The [full independent evaluation report](#) and the [evidence supplement](#) can be found on the CW+ website.