

# The role of the neonatal care coordinator: a report from the Northern Neonatal Network team

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Northern Neonatal Network

In April 2021, the Northern Neonatal Network established the first neonatal care coordinator team in the UK. With the aim of enhancing the family experience, the team acts as a conduit between parents and health professionals, focusing on facilities, resources and support for families. Early priorities are to support units to achieve Unicef Baby Friendly and Bliss Baby Charter accreditation, embed a culture of family-integrated care and develop a parent advisory group. We are working towards reducing variation in practices across the network in order to standardise care for babies and families. Sharing best practice and celebrating successes is integral to the role.

## About the team

The neonatal care coordinator role at the Northern Neonatal Network (NNN) is new. Our team comprises three care coordinators working across the 10 neonatal units in the NNN (FIGURE 1):

- Claire supports the neonatal units at Northumbria Specialist Emergency Care Hospital (Cramlington), University Hospital North Durham, Queen Elizabeth Hospital (Gateshead) and Sunderland Royal Hospital
- Sue supports the neonatal units at Darlington Memorial Hospital, University Hospital North Tees (Stockton) and James Cook University Hospital (Middlesbrough)
- Ailie supports the neonatal units at Cumberland Infirmary (Carlisle), West Cumberland Infirmary (Whitehaven) and the Royal Victoria Infirmary (RVI) in Newcastle.

Claire and Sue each have 30+ years' experience as neonatal nurses within the network and Ailie, a neonatal occupational therapist, set up the first acute occupational therapy service in the NNN three years ago.

## The role of the neonatal care coordinator

Our role evolved from the Neonatal Critical Care Review (NCCR), which highlighted a national need to improve the experience and support for families within neonatal care. This would be achieved by developing and investing in support for parents, as evidence shows that outcomes are better for babies whose parents are able to play an active role in their neonatal care. The NCCR deliverables focus on key areas, including:

- improving the facilities available to parents while their babies are receiving neonatal care – their physical accommodation, the support they receive, their psychological needs
- enhancing and increasing the ability for parents to become more of a primary carer, through approaches such as family-integrated care (FiCare)



**FIGURE 1** From left, Ailie Hodgson, Sue Thompson and Claire Campbell.

- supporting neonatal units to achieve accreditation to national initiatives to improve care, eg Bliss Baby Charter and Unicef Baby Friendly (neonatal) standards.
- NHS England funded the role of care coordinators to have a direct impact on family experience. With a remit for developing, improving and enhancing FiCare in all neonatal units, the care coordinators are connecting and coordinating with units and other leads to support their local work, fostering a culture where FiCare is embedded in everyday practice. As well as improving the facilities and support available to families during their baby's inpatient episodes, the role aims to provide a seamless service across the network and beyond, and to support parents in preparation for the transition to neonatal outreach and/or paediatric services. It is envisaged that working with units on these national initiatives will improve the outcomes for families and babies in neonatal care settings.

The following report gives an overview of our work since the neonatal care coordinator team was established in April 2021.

### Unicef neonatal standards/accreditation

The network is in the fortunate position that all 10 units have received NNN funding to achieve Unicef Baby Friendly Initiative (BFI) neonatal standards stage 3 accreditation. The NNN has funded two courses for staff to attend five days of training with Unicef. This training includes embedding neonatal standards, audit training and train-the-trainer. All units now have fully trained staff to lead the programme and are supported by the care coordinator team. At present we have one unit that has achieved stage 3 accreditation and nine units working towards stage 1. We recently worked alongside the regional infant feeding lead, to host an education day for staff and unit managers working towards their BFI accreditation.

### Bliss Baby Charter audit

The NNN has funded all 10 units to gain the next stage of accreditation within the Bliss audit. Some units have achieved this and others are still working towards it. All units have a Bliss lead and are working with the care coordinators to improve compliance with the audit. As care coordinators, we have chaired national discussions with other care coordinators and Bliss to ascertain how other networks are progressing with their Bliss audit.

### NNN guidelines

The care coordinator team is currently reviewing and updating the FiCare and developmental care guidelines to improve consistency of care and communication for families across the network. Network guidance to decrease inconsistency is a key principle within the Bliss audit. These guidelines will be hosted on the NNN website when ratified for use (<https://nornet.org.uk/professionals/guidelines>).

### Neonatal Nurses Association scholarship

We are incredibly grateful to have won funding from the Neonatal Nurses Association's (NNA) travel scholarship 2021/22 for our project 'Examining how harmonisation of aims is achieved between parents and clinicians in neonatal units renowned for having an effective and embedded FiCare model'.

Working co-productively with our Parent Advisory Group (PAG) member, Rachel Collum, we identified Sweden as a country that has successfully embedded FiCare principles into some of its neonatal units. We are keen to explore their experiences and we are very fortunate to be working with Professor Renee Flacking, who has helped us to identify relevant Swedish units. We plan to visit Sweden in September 2022 with the following aims:

1. Identify gold standard units in Sweden that successfully achieve FiCare in practice.
2. Understand and conceptualise the parent voice and staff experience within a FiCare context.
3. Identify and understand facilitators and barriers to FiCare in practice and how these triangulate between parents and medical teams.
4. Investigate training in FiCare for student nurses and how to embed FiCare into practice and culture.

### Network app (NorNet)

The network has funded an updated app with a new provider to help ensure parents have the most up-to-date information about the Northern Neonatal Transport Service (NNETS) and all units in

our network, alongside access to accurate information about caring for their baby in a neonatal unit and the ability to give feedback about the services they received (FIGURE 2). We have also added some new sections for each hospital, antenatal information, family support, top tips for parents by parents, and a section on going home.

### Perinatal mental health

Emotional support for families is variable across the network and we have been exploring how to ensure we have a universal service for all families. The Improving Access to Psychological Therapies (IAPT) programme is now established in every area of England, although IAPT provision can be difficult to access when

families are moved away from their geographical home area because of the way it is funded. We have agreement from several IAPT providers to place a practitioner within some of our units for one session per week. We are hoping to upscale this to cover all units and, to ensure equity of provision, we are currently developing a pathway with IAPT providers across the NNN.

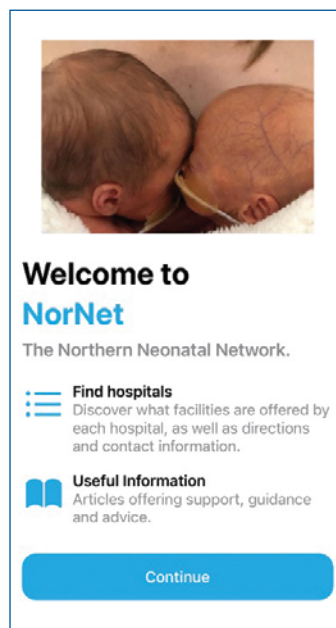
We have had many discussions with our PAG around perinatal mental health support. Our parents feel they get the most support while in a neonatal unit; the bedside nurse and peer support are the primary support networks described by parents. To help clinical nurses support families, we are developing a bespoke training programme in collaboration with a clinical psychologist, the care coordinators, unit staff, parents and the IAPT. We are also working with the maternal mental health services to ensure the needs/voices of families within neonatal units across the NNN are heard.

### Allied health professionals

Allied health professionals (AHP) working within neonates offer expertise in:

- recognising sensorimotor issues
- helping with swallowing difficulties
- optimising nutrition
- supporting families with sensory and neurodevelopmental protective strategies
- facilitating essential tasks such as bonding, feeding, closeness and movement in a preventative capacity.

As care coordinators, we have scoped current AHP provision within the network (both acute and community-based), using Getting it Right First Time (GIRFT) data, liaising with network AHPs and regional therapy service leads to identify gaps in provision. We have established a Collaborative AHP and PAG Steering Group with regular meetings and, as a result, have co-created a gold standard pathway of AHP input. We have designed a poster for display in units describing the AHP roles and raising



**FIGURE 2** The network app can be updated as often as required, which was especially important during the changes to family access during the COVID-19 crisis.

the AHP profile (FIGURE 3). We have discussed various challenges including geographical limitations, lack of awareness of availability, funding and education, the importance of early intervention to minimise developmental deficits and the importance of AHPs seeing the baby and family as a whole entity. Now that the NNN AHP leads have come into post, we look forward to working with them to improve access to AHP provision for families in the network.

### Parent survey/feedback

We monitor parental feedback continuously within the network through the parent survey given to families at discharge from the unit. We have also developed a feedback option on our new app. The network parent feedback survey was developed a number of years ago to capture what care for babies and families in the region looked like, and to ensure families' experiences were equitable. The survey has been updated by the care coordinator team to ensure questions are family friendly, current and capture recent developments and changes within the network. The survey has been updated utilising input, feedback and consultation from a range of parents to ensure it gathers information that parents think is important, as well as what the network hopes to capture. As care coordinators, we will support units to gather this feedback and implement the survey electronically to ensure we are collecting as much data from the whole network and from as many parents as possible.

### Health visitor support

The role of health visiting (HV) teams changed dramatically during the COVID pandemic and many HV teams were relocated to clinical areas, leading to fewer home visits and less direct family support. We are reviewing a standard operating procedure (SOP) previously developed by a collaboration between the Middlesbrough HV team and the network Bliss nurse. The Darlington HV team has reviewed and updated the SOP post-COVID. The aim of the team is to ensure early contact with all neonatal families, and also a minimum of weekly contact between the HV, family and neonatal unit. This initiative is a pilot, which, if successful, the Institute of Health Visiting is hoping to embed into all HV teams across the NNN.

### Education and training

It is important to present the role of the care coordinator and the work we are doing to a wide audience, as neonatology is closely linked to many other specialties, especially obstetrics, antenatal and postnatal, mental health and public health services. We are active members of the Maternity and Neonatal Safety Improvement Programme and have presented how we can work in harmony with the aims of the programme by aiming to reduce variation in the experience for families across our network. Since we value parents as partners, we always aim to have a parent presenting alongside us, because embedding parents as partners in care can only be achieved when the parent voice is heard at every level.

We have supported the pre-qualified in specialty (QIS) and QIS training days within the NNN and through this we disseminated information about our role and the projects we are supporting. We also gained valuable information from network staff about their worries, expectations and hopes for FiCare, which have been embedded into our implementation plan for FiCare. Additionally,



FIGURE 3 A poster describing the various AHP roles, for display in units.

we have contributed to developmental training day preparation and delivery, specifically at the RVI, but with the hopes of expanding this training to other units. We have taught post- and undergraduates at the University of Northumbria on the role of occupational therapy in neonates.

### Care coordinators present...

The 'Care coordinators present' initiative was set up in 2021, using a well-established and embedded model from a palliative care nurse specialist. The initiative was developed to share practices, projects and collaborative working using a digital platform. The sessions run monthly via Microsoft Teams. We organise and facilitate a range of educational topics; we have guest speakers and ensure every session includes a parent as a co-presenter. The sessions have enabled showcasing of local work and successes of working together as a network, with parents and national counterparts and colleagues. Feedback has been excellent and interest is growing each month.

### FINE training

We are developing a NNN Family and Infant Neurodevelopmental Education (FINE) faculty, under the direction of Inga Warren (finetraininguk.com). We hope that by having a faculty within the network we can make training more accessible for all staff. Within our faculty we currently have three instructors and other faculty members as clinical advisors to assess good practice and gaps in knowledge. Our aim is to ensure the network has a sustainable course with qualified trainers to benefit all staff.



## Family Integrated Care Implementation Group

The Family Integrated Care Implementation Group (FIG) was established in 2021 and includes clinical staff representatives from all 10 units, parents and AHPs. The group is collectively working on a regional approach to implementing and embedding FiCare in all 10 units within the NNN. The care coordinator team has conducted a series of face-to-face conversations with parents to gain feedback and establish what current practice feels like for parents. This will help to establish baseline FiCare data alongside digital questionnaires. We are also working with the network quality improvement lead and FiCare representatives (including parents) to develop FiCare education and resources to support units.

### Ei SMART training pilot

We are delivering network-wide training for all staff around the Ei SMART evidence-based framework ([www.eismart.co.uk](http://www.eismart.co.uk)), which aims to improve developmental outcomes and is of interest to anyone working with high-risk infants in the neonatal intensive care unit and the community (FIGURE 4). It is an approach where S (sensory), M (motor), A (attention and regulation) and R (relationships) form part of every interaction and intervention with the infant. The Ei SMART approach is co-produced T (together) with parents and the aim is to seek to understand the lived experience of the infant.

This training pilot is the first time the Ei SMART team has delivered network-wide training and we feel really honoured to be delivering this education alongside them. The aim is to embed the framework across all 10 units and staff working in neonatal follow-up.

### The PAG

A parent panel was set up in 2021 to look at the NCCR and this has since evolved into our PAG. The diversity of the group is actively encouraged and the care coordinators are working with all units to get representation from their local communities. We have had discussions with equality and diversity representatives, local charities and organisations to ensure all parents have a voice. We have worked with the Family Nurse Partnership to explore how to engage young parents; consequently, the PAG has a growing number of young mums. Monthly online meetings help inform discussions around all aspects of neonatal care. The PAG has grown into a cohesive and supportive group of parents serving a two-fold purpose:

- providing a forum in which parent voices can be heard
- offering peer support and a space for parents to share their experiences to inform practice.

The parents are involved in many work streams, including the development of a communication resource co-produced with Bliss entitled *Our Journey*. This is designed to enhance communication between healthcare professionals and parents and encourages FiCare, parental involvement in decision making and partnership working. The resource will help families transitioning to home and allow information to be shared between families and caregivers without repetition of sensitive and triggering conversations.

We have worked creatively with members of the PAG to gather their stories and experiences in a variety of ways including working with a local artist using collage to create visual depictions



**FIGURE 4** Ei SMART aims to deliver consistently effective early intervention for high risk preterm and term infants.

and highlight emotive words, thoughts and feelings of families that have a baby in neonatal care. We are looking at other ways to feedback parents' stories, including creative writing as a therapeutic and exploratory tool. Plans are underway to develop a series of podcasts of parent stories alongside health professionals talking about their roles.

### National Neonatal Care Coordinator Group

The National Neonatal Care Coordinator Group (NNCG) was established in April 2021. Claire Campbell is Chair and Lisa Leppard from Thames Valley and Wessex Operational Delivery Network is Vice Chair. The group was set up to encourage peer support and sharing of best practices. Each care coordinator coming into post in the UK has been personally welcomed. Being the first established care coordinator team in the UK, the NNN team has acted as a support mechanism. The group set up a Future NHS workspace platform to share resources among the NNCG community, and has several active sub-groups. The NNCG structure is aligned to the National Lead Nurse Group and both groups feed into one another.

The NNN care coordinators hosted the first NNCG event at the end of March 2022. We welcomed care coordinators from around the country and shared some of the incredible work the NNN is achieving, listened to parents' perspectives, highlighted some of the collaborative work we have been involved in, and learned about the work other care coordinators are doing nationally. Feedback from the event was very positive and will be utilised for planning further events.

### Conclusion

Much was achieved in our first year as care coordinators. Collaboration and co-creation are key to our successes. We will continue to strive for better care and resources for our neonatal families and health professionals. At the centre of everything we do are the baby and family. Culture change is occurring slowly and effectively and will continue to do so with such roles as the care coordinator; we learn and we adapt and the parent voice is always with us. We end the article with a quote from a PAG mum: "The care coordinators hold the megaphone to us for our voices to be heard, which will influence positive change for future babies and families within neonatal care."

The authors send thanks to all of the units in the Northern Neonatal Network for their amazing support.