

# FAMILY INTEGRATED CARE REPORT

An overarching delivery plan ensuring  
that families are kept at its centre as  
primary care givers

2025-2028



Author: Lisa Leppard

Lead Care Coordinator  
Thames Valley and Wessex  
Neonatal Operational Delivery  
Network



 **THAMES VALLEY & WESSEX**  
**NEONATAL NETWORK**

## **Executive Summary**

Thames Valley and Wessex Neonatal Operational Delivery Network (TVW ODN) is working to enhance Family Integrated Care (FIC) within neonatal services. The Report and Strategy aim to integrate families at the heart of care delivery, ensuring that parents/carers remain the primary caregiver in the neonatal setting.

The documents align with key recommendations from the Neonatal Critical Care Review (NCCR), Baby Charter Framework, BAPM FIC Framework, and the NHS Delivery Plan for Maternity and Neonatal Services, ensuring that families have an active role in their baby's care. It is designed to ensure that family members feel supported and empowered in their caregiving roles, throughout their neonatal journey.

Crucial to FIC becoming embedded as an ethos of care on neonatal units is the motivation and training of all neonatal staff to provide high standards of care that align with the values of FIC. This will be achieved by providing training and support to improve communication skills, family engagement techniques, and providing staff with the resources needed to ensure families feel central to the care decisions made about their baby.

It is the Multidisciplinary Team's (MDT) responsibility to ensure that FIC is embedded into the culture and ethos of care for babies and families of all neonatal units.

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## 1.0 Glossary of Terms

**AHP** Allied Health Professional

**BAPM** British Association of Perinatal Medicine

**BFI** Baby Friendly Initiative

**CCs** Care Coordinators

**CP** Clinical Psychologist

**FCC** Family Centred Care

**FIC** (or FiCare) Family Integrated Care

**HD** High Dependency

**ICS** Integrated Care System

**KSS** Kent Surrey and Sussex

**LMNS** Local Maternity Neonatal System

**LNU** Local neonatal units: provide care for babies over 27 weeks gestation at birth (27+6 for multiples)

**MDT** Multidisciplinary team - a team of health care professionals for different disciplines

**NCCR** Neonatal Critical Care Review

**NICE** National Institute for Health and Care Excellence

**NICU** Neonatal Intensive care units: Intensive Care is care provided for babies who are the most unwell or unstable and have the greatest needs in relation to staff skills and staff to patient ratios.

**ODN** Operational delivery network- which are focused on coordinating patient pathways- between providers over a wide area to ensure access to specialist resources and expertise.

**PAG** Parent Advisory Group

**PNA**s Professional Nurse Advocates

**QI** Quality Improvement

**PFEL** Parent & Families Engagement Lead

**SCU** Special Care Units – provide special care and transitional care for their local population.

**SE** South East

**TCU** Transitional Care Units

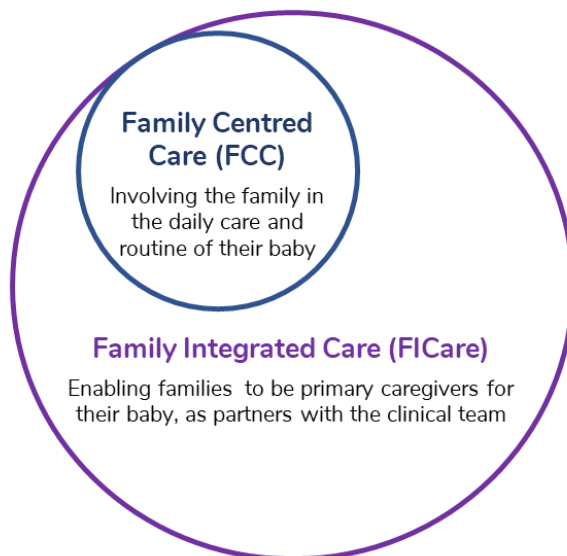
**TVW** Thames Valley and Wessex

**UNICEF** United Nations International Children's Emergency Fund

## 2.0 What is Family Integrated Care (FIC)

FIC enables and empowers parents/carers to become confident, knowledgeable, and independent primary caregivers. It ensures that parents/carers, baby, and wider family members are valued as soon as possible, ensuring the balance of necessary medical care with the nurturing bond and love that only they can provide for their baby.

Building on the foundations of Family Centred Care (FCC), FIC is supported by the core principles outlined in the [Bliss Baby Charter](#) and extensive research. FIC is a natural progression of FCC, from involving families in care to enabling them to be equal partners in the care team and primary caregivers (BLISS, 2024).



### 2.1 TVW Vision

In neonatal care, parents and carers are seen as primary caregivers, central to the care and planning for their baby. The goal is to empower them to feel informed, confident, and independent. Neonatal multidisciplinary teams (MDTs) will collaborate with parents and carers to care for their baby.

The ODN Care Coordinators, AHPs and Psychologists will work alongside the Parent Advisory Group (PAG) and local teams in coproducing FIC resources and materials for both parents and staff, ensuring that the parent and staff voice is heard and reflected throughout. Families are integral to the MDT. Our vision for the FIC model is to enable families to become part of the core team.

With the funding for Allied Health Professionals (AHPs), Psychology, and the introduction of FIC Leads and Repatriation Link Nurse quality roles, the neonatal experience for families will be further supported, as will the staff caring for them on our neonatal units. Whilst units across the ODN will look different depending on activity, size, specialism, and population, the care and support families receive should be consistent.

By supporting the development of Transitional Care Units (TCU) and reducing term admissions to the neonatal unit, this will promote the minimal separation of mother and baby whilst in hospital. Promoting earlier discharge with the support of multidisciplinary outreach services

and the development of hospital at home programmes will also enable parents/carers to be the primary care givers at home as soon as possible.

*The vision is to cultivate a highly skilled and knowledgeable workforce capable of empowering, supporting, and mentoring parents to care for and advocate for their baby. The TVW ODN will ensure that all staff have access to evidence-based training, fostering a culture of partnership between families and staff both in hospital and at home. (TV&W ODN Workforce Strategy 2024)*

## 2.2 Transformation

Since the launch of the NCCR Transformation Review in 2019 the TVW ODN CCs have been working with providers to ensure a safe and consistent level of service delivery in whichever neonatal setting the baby and family are being cared for. There has been a significant cultural shift within neonatal care since the introduction of new roles, such as Link Nurses for repatriation, FIC leads, introducing parents and service users in co-design and production and funding for quality roles such as risk/governance roles. While this transition will take time, it is essential to recognise the changing team dynamics that accompany these roles. Managing this change will require senior leadership both at Network and unit levels, in managing expectations and developing the capabilities of these newly established roles, ensuring alignment with existing team structures.

*NCCR (2019) and Ockenden (2021) has funded a more equitable multidisciplinary neonatal workforce, including AHPs and psychology provisions, across the ODN to support FIC practice.*

*The Neonatal Care pathway is now well placed for continuation of transformation with NCCR and Ockenden funding in place. Pivotal to the success of transformation is a consistent, sustainable, highly skilled, multi-professional, competent workforce across the TVW ODN, working in partnership with service users and maternity services to ensure optimal quality care and outcomes for babies and families. The Ockenden funding was about the gaps in service provision on the ground and to try to address this. Funding for Network AHP and CCs roles was through the NCCR, and it is this funding which is being utilised to enhance support given to our outreach services. (TV&W ODN Workforce Strategy 2024)*

## 3.0 Introduction and Context

In Pineda et al (2017) paper, a predictive study to look at predictors and relationship to neurobehavior, and developmental outcomes, it identifies, high quality neonatal care must include a substantive role for parents/carers in the care of their baby; in this respect, neonatal care differs from many branches of inpatient medicine. Parents/carers are not bystanders as illness develops and resolves but perform an active role as a member of the care team. To perform this role, and to minimise morbidity, parents require support and facilitation by a service that has appropriately focussed and trained nurses and AHPs working alongside medical staff. There are various models of care that can support parents in this way and the Bliss Baby Charter has described how the service should offer family centred facilities.

Guez-Barber & Pilon (2024) state that ‘fostering the impactful role of parents as teammates optimises neurodevelopmental outcomes in NICU and beyond’. Family involvement should not be tokenised or seen as a ‘checkbox.’

The NCCR (2019) also highlights how ODNs and LMNSs should work together to ensure that parents are given the opportunity to be involved in the care of their babies.

3.1 Action 6 of the NCCR Transformation Plan states:

BLISS found in their 2022 survey, that 82% of families did not have access to overnight accommodation and this limited their choice in being involved in their baby’s care 24/7. Parents/carers described leaving their baby/s at night to return home as one of the hardest parts of their neonatal journey.

The average cost to families travelling daily to the neonatal unit was £109 per week. The time and cost to parents/carers could be reduced if they were able to be resident, or near their baby/s overnight.

‘The evidence shows that outcomes are better for babies whose parents can play an active role in their neonatal care. Their inclusion benefits the neurodevelopment of the baby during critical periods of early life and promotes long-term quality of life and family cohesion.

**Breast feeding is more successful, bonding is encouraged, and parental stress is reduced, all of which have long term benefits for babies and families.**

**Parents require support and facilitation by a service that has appropriately focussed and trained nursing or AHP staff, working alongside medical and nursing clinical practice staff.**

**Parents need facilities and resources for them to choose to be resident with their new-born or sick baby for some or all the 24-hour period if their circumstances permit.**

**Support for travel (car parking etc.) is equally important as babies often remain critically ill for weeks or even months, particularly when born at extremely low gestational ages.**

**LMNSs and ODNs should work together to profile the provision in local providers by reviewing the extent to which providers are integrating families into care and providing developmentally supportive care, including information on, and access to, emotional wellbeing and psychological support and the provision of resources and accommodation’ (NCCR 2019).**

BLISS successfully campaigned for the NHS Long Term Plan to include a commitment to invest in parent accommodation on neonatal units. This commitment was renewed in the Three-Year Delivery Plan for Maternity and Neonatal services in 2023, this is yet to be delivered, but services should continue to develop business cases where additional funding is required to support capital projects to improve parent/carer facilities.

## 3.2 Parental and wider family access

Since the end of the recent pandemic there is an expectation that all units within TVW now have open access to parents and siblings. Parents/carers are not visitors they are partners in their baby's care. BLISS (2021) stated that wider family access should be extended to incorporate key visiting times for families. TVW ODN encourage all units to overcome barriers to open access for parents and siblings. Variations in permitted numbers vary across the ODN dependent on each neonatal unit's footprint. However, a parent's wish to be with their baby should be discussed with the unit, documented, and disseminated across the team.

## 3.3 Equity, Diversity, and Inclusion

Although equity and equality are often used interchangeably, they are quite different. Equality means that everybody has access to the same resources and opportunities, regardless of their circumstance. Equity is recognising individuality, and their backgrounds have strengths and limitations, meaning that some will need more support than others to ensure equity (bnssg.icb.nhs.uk).

### 3.31 TVW ODN Commitment to Equity

TVW ODN is committed to ensuring all the families across the Network receive consistent and equitable care, no matter where that care setting is, or what their social, cultural, or educational background.

By actively listening to families through feedback, surveys, and collaboration with Maternity and Neonatal Voices Partnerships (MNVPs), TVW ODN strives to ensure that the voices of all groups, especially those most at risk of health inequalities, are heard.

### 3.32 Actions Towards Equity:

- Recruiting a diverse membership to the TVW PAG to provide broad experiences into ODN-led projects. TVW PFEL, has conducted focus groups. An example of which was in Wexham Park, encouraging families from all backgrounds to become actively involved with neonatal service development. The PAG are working to support provider units to engage with parents from diverse backgrounds to co-produce local FIC projects.
- Ensuring that interpreting services are accessible across the ODN to support non-English-speaking families or where English is not their first language.

The BLISS report in 2022, researching South Asian communities experience of neonatal care highlights that 'parents who did not speak English as their first language were more likely to report a poor experience'. <https://www.bliss.org.uk/news/2022/bliss-launches-new-research-of-south-asian-communities-in-neonatal-care>

- Making all written information easily accessible to everyone.

- Involve families in making safe and informed decisions, ensuring that parents/carers understand proposed treatment plans and expected outcomes. Parents/carers need to understand the context of decision making no matter what their background is.

This can be achieved by:

**Using visual aids, use simple language avoiding medical jargon. Providing written summaries in appropriate languages and in a format that is acceptable to the individual. Respect cultural beliefs and practices within families. Recognising each family is different and tailoring communication to meet their needs, this may involve adjusting the pace and the amount of information shared and how this is presented.**

- Collaborating with local providers to support their endeavours in promoting equitable care.
- Supporting providers to deliver compassionate and high-quality care for bereaved families including appropriate accommodation, which is easily accessible but separate from maternity and neonatal units, in line with Theme 1 of the 3 Year Delivery Plan for Maternity and Neonatal Services. ([B1915-three-year-delivery-plan-for-maternity-and-neonatal-services-march-2023.pdf](#))

## 4.0 Aligning with BAPM and how TVW will achieve those aims in our Neonatal Units.

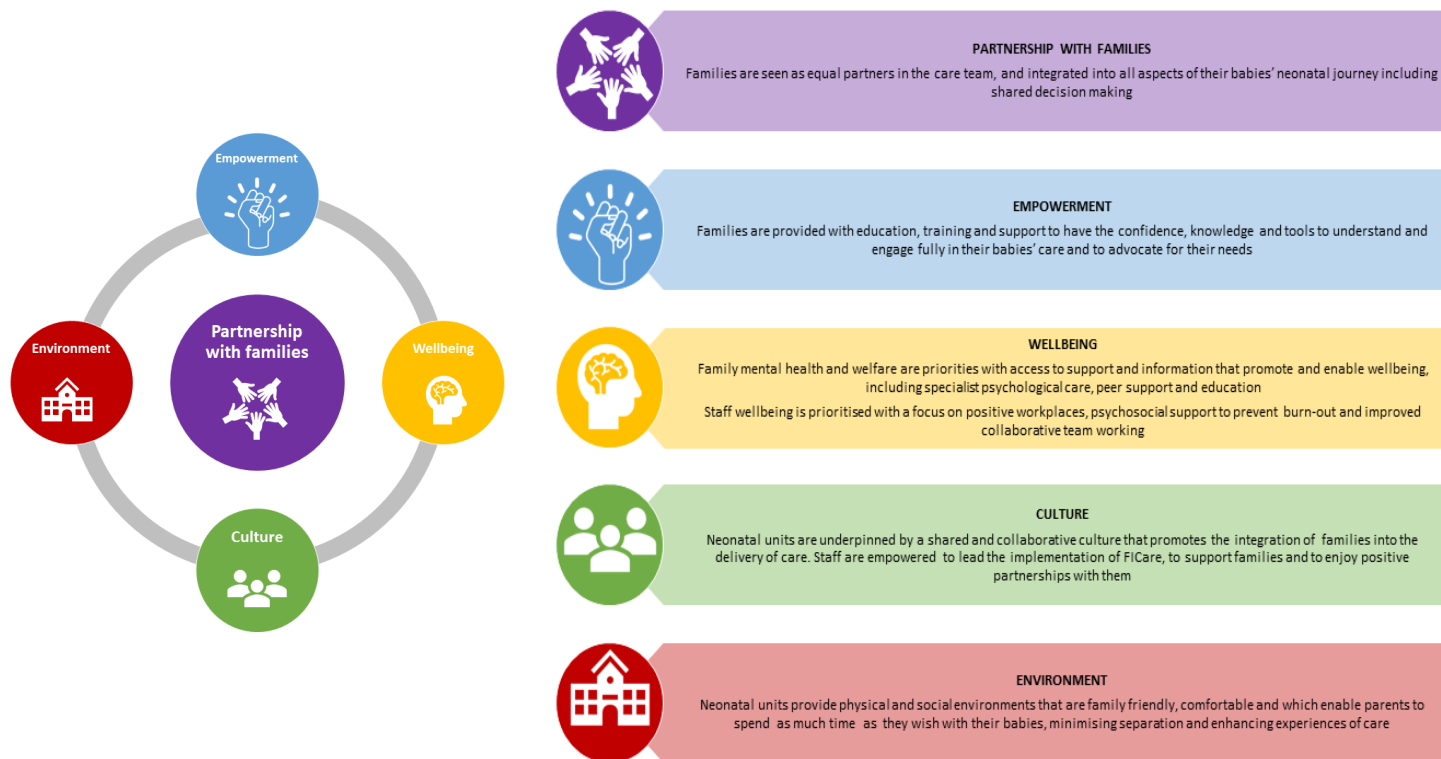
[Family Integrated Care | British Association of Perinatal Medicine](#)

### 4.1 The Model of FICare

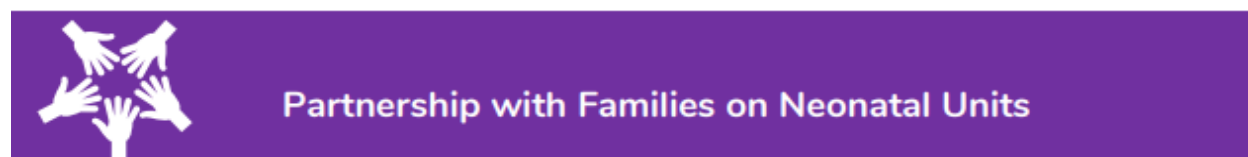
This model of FIC (Figure 2) includes five key principles (Figure 3). Embedding each of these principles into the development and delivery of care on neonatal units and within networks will enable the growth of a FIC philosophy.

These principles are based on the “pillars” of FIC first developed by O’Brien and colleagues in 2013 at the Mount Sinai Hospital in Toronto, which inspired early FIC programmes in the UK and internationally. FIC has since evolved in different countries and care settings, and over time there has been increasing recognition that ‘partnership with families’ is one of the most challenging culture changes to achieve and embed in practice. For this reason, the International Steering Committee for Family Integrated Care advocates that ‘partnership with families’ is included as an overarching principle in FIC models implemented in the future. (BAPM 2021)

**Figure 2. The model of FiCare (BAPM 2021)**



## 5.0 BAPM 5 Key Components and the concepts of how TVW will commit to the BAPM Framework



### Examples of this in TVW are:

- Across TVW ODN, we are working towards all units recognising parents/carers as primary care givers by involving them in all aspect of their baby's care, treatment planning and ensuring that parents/carers are invited to be present and participate in daily ward rounds and decision making for their baby. Recognising them as the experts in their baby.
- Parent/carer feedback through the TVW ODN Parental Survey. Feeding the results to teams and MNVPs.

- The Parent & Families Engagement Lead is developing strategies with local MNVPs to ensure the neonatal parental voice is heard throughout the ante-natal, perinatal, and post-natal journey to ensure both are working together to better support families/carers.
- Using Appreciative Enquiry (AI) alongside staff on the ground with current parents/carers to gain insight and help inform the future of neonatal care. Supporting local teams to work collaboratively with local families on QI projects from their concept to completion.
- Offering guidance and supporting local peer support for parents/carers. Establishing FIC teams in neonatal units with families at their heart.
- TVW FIC Group meetings, sharing good practice within service providers and all the working groups together to ensure that the FIC philosophy is threaded throughout all the workstreams, to ensure equity of FIC provision across TVW.
- Creating, developing, and supporting teams with tech innovations to support parent/carers in their care e.g. 3D Virtual Unit Tours, Padlets, VCreate videos and the network website.
- Developing a PAG to co-produce and ensure a service user voice is included on QI projects across TVW. Continual recruitment into this group ensuring sustainability and diversity.
- Establishing a Parent Tube Feeding Learning Package to support parents/carers to learn how to safely feed their baby via a tube. The aim is this training is accepted and honoured by all units across the Network no matter where the original training is completed within TVW. Parents /carers will share the training package with staff if they are repatriated closer to home or transferred for further specialist neonatal treatment.



## Empowerment on Neonatal Units

### Examples of this in TVW are:

- Ensuring families have open access to their baby/s at all times. Never seen as visitors.
- Fully orientating parents/carers to units before, or on admission and as they move through units to different rooms and levels of care. Helping units develop their FIC philosophies to ensure families are fully integrated into the delivery of care to their baby.
- TVW has developed: Journey cards, Padlets, VCreate videos, 3D Neonatal Tours, Parent Tube feeding Package, TVW Webpage, to promote the consistent delivery of FIC across

all units. These resources provide families with Network pathways including optimal place of delivery, specialist care and timely repatriation closer to home.

- The Repatriation Framework has provided guidance to health care professionals in timely repatriation of infants to a neonatal unit closer to home for ongoing care. This is closely aligned to the BAPM, Safe and Effective Repatriation of Infants Framework, launched in 2023. Several TVW team members were involved in developing the BAPM framework, showing their expertise and commitment to improving neonatal care practices, with many of the initiatives developed in TVW and incorporated in the framework.
- Parents/carers being central in decision making and planning of care. No parental restrictions on ward rounds. Parents/carers are actively encouraged to be present and when ready, actively participate in the discussions around their baby on ward rounds with medical teams. Supporting the NHS ethos of 'no decision about me without me.'
- For parents/carers to be viewed as the expert on their baby and their views canvassed and respected at all stages of care, where possible.
- TVW is committed to supporting national, regional, and local campaigns ensuring the neonatal voice is present at all levels. Several of the ODN team and PAG members have worked with developing various frameworks e.g. Repatriation, Outreach, and Workforce.



## Wellbeing on Neonatal Units

### Examples of this in TVW are:

- Provision of psychology support through Ockenden funding across TVW.
- Planning to develop provider business cases for peer-to-peer support models locally for families, with appropriate supervision of those supporters through the Network and local Psychologists.
- NCCR Transformation funding for FIC lead nurses on all 14 Neonatal Units. These posts will help support families and staff with education, support, and engagement with local charities, third sector organisations and local community support.
- Implementation of Repatriation Link Nurses across TVW to support families when receiving care away from their locality, and planning repatriation of those families and baby/s closer to home. Development of the Repatriation Framework to ensure families move appropriately and seamlessly across the Network, ensuring consistent care. The Link Nurses are working collaboratively between units to improve the consistency and continuity of care across the Network and to ensure the timely repatriation of baby/s and families.

- TVW have developed various resources for families which are translatable into several languages and easy to read formats, to ensure equity and are supporting teams locally to explore translation resources for families.
- Encouraging local FIC teams with the creation and development of parent/carer support groups, where parents/carers can meet to share experiences and gain support from other neonatal parents/carers and neonatal professionals.
- CC, AHP, Psychologists and PFEL are working closely with local teams to develop local projects ensuring families are at the core of all projects from conception to completion. Supporting local teams to work with third sector organisations and charities supporting neonatal care, to ensure equitable access to peer support / parent groups.
- The CCs are part of the wider National Care Coordinator Group ensuring good practice and learning is shared regionally and nationally and informing the TVW ODN NCCR Implementation plan.
- Professional Nurse Advocates are available to provide training and restorative supervision for neonatal colleagues.



## Culture on Neonatal Units

### Examples of this in TVW are:

- TVW ODN team is actively involved in staff education across the Network to ensure the FIC philosophy is embedded into neonatal QIS Foundation and QIS Specialist education programmes and local mandatory training.
- CCs have developed a training package and a Find the FIC resource to help staff explore what FIC is and how it can be integrated into the care the babies and their families receive.
- AHPs are in post in many units and are actively engaged with FIC training and support for families and staff, helping to embed FIC as the philosophy of care and neurodevelopmental care.
- Psychologists are supporting families and staff with trauma informed care and practice (see resources).
- The CCs are working locally with FIC teams across the Network to ensure parents/carers have the choice and opportunity to be actively involved in all aspects of their baby's care.
- Communication training utilising a trauma informed approach is being delivered by the TVW team to staff across the Network.

- FIC training is available to support staff to coach and mentor parents/carers on neonatal units.
- Development of the TVW FIC group to share best practice and resources with providers to ensure equity and consistency of care and avoid the duplication of work.



## Environment on Neonatal Units

### Examples of this in TVW are:

- CCs are working with local teams in reviewing their unit footprint and the facilities that are available to families. Supporting them with bids for capital funding to improve current facilities.
- Scoping of current provision of parental accommodation and support given to units to explore alternatives for additional capacity.
- Transitional care across TVW has been scoped and plans are progressing to ensure sufficient capacity is available in all service providers, with appropriate staffing and training to reduce avoidable separation of mother and baby.
- Funding for BFI in all units has helped ensure that there is suitable support for expressing mums and further support for teams developing their current practices.
- TVW supports parents/carers being present and active participants on ward rounds, with developing staff training and resources to ensure that this opportunity is available to all parents.

## 6.0 Where we are now.

TVW ODN has employed two Lead Care Coordinators and two Local Care Coordinators and a Parent and Families Engagement Lead (PFEL) who lead on the implementation of the NCCR transformation workstream to Enhance the Experience of Families throughout their Neonatal Care. They work alongside local neonatal teams and the PAG, to embed the delivery of high-quality FIC. With NCCR quality role funding from NHSE, there are now FIC Lead Nurses recruited in 12 of the 14 neonatal units, the aim is to have 14 in post by Spring 2025. There are 9 Repatriation Link Nurses in post with a further 5 in post by early 2025. These are currently not funded and are supernumerary at present. The risk of this is, that during time of high activity and acuity, staff in these roles will be utilised to fill clinical gaps in the workforce, then parents/carers may not then have the support and service that they were expecting, which may lead to miscommunication, less support and delayed repatriation of babies closer to home.

## 6.1 FIC Lead Nurses: Key to Partnership Empowerment Wellbeing Culture Environment

With NCCR Direct funding, TVW were able to recruit in post Practice Educators for all 14 units. The remaining funding was used to recruit 0.2 WTE Band 7 FIC Lead nurses for all units who did not already have dedicated FIC Lead role. The 0.2 WTE was based on cot days due to the differing elements to this role.

The TVW ODN team is working with all units locally to implement and embed FIC Leads in all units. The challenges of this new transformation role are supporting change in the philosophy in care and change management. Preparation and training for this role are key to its success and is essential for the adoption and embedding of FIC on all the units across TVW. Training and support are being developed by the wider TVW MDT and those new into their roles would be encouraged to enrol on the ODN Leadership Programme, empowering those in post to be able to lead and manage change within their teams.

The table below highlights those in post, with a gap analysis of what would be required based on 0.2WTE per 1000 care days. The CCs are supporting the FIC leads as they come into post with training, resources, change management support and peer support. This is achieved by a monthly peer support group and face to face working days planned for 2025. These posts aim to reduce the wide variations in FIC that families experience across TVW, by working together and sharing good practice. We continue to explore avenues to develop these roles further.

### Fic Leads in post as of 2025.

	Cot days Oct '23 - Sep 24					0.2WTE / 1000 days
	IC	HD	SC	Total	In Post	
Dorset County	30	260	1006	1296	0.2	0.2
HHFT - Basingstoke	108	482	2091	2681	0.2	0.4
HHFT - Winchester	171	480	1869	2520	0.2	0.4
JRH, Oxford	4044	3804	5064	12912	0	1.0
Milton Keynes	319	1212	3292	4823	0.8	0.7
PAH, Southampton	3098	2804	4737	10639	0.93	0.9
Poole	296	1469	3382	5147	0.2	0.7
QAH, Portsmouth	2435	2058	5091	9584	0.2	1.0
Royal Berkshire	271	1340	2664	4275	0.2	0.5
Salisbury	61	609	1615	2285	0	0.3
St Marys, IOW	11	67	618	696	0.3	0.1
St Richards, Chichester	30	218	1650	1898	0.125	0.3
Stoke Mandeville	340	1304	3318	4962	0.2	0.7
Wexham Park, Slough	250	1119	2820	4189	0.2	0.6
<b>Total</b>	<b>11464</b>	<b>17226</b>	<b>39217</b>	<b>67907</b>		

TVW has designed and implemented FIC training for staff across the Network, CCs will deliver this training, AHPs and Psychologists alongside local teams. Teaching resources, developed and co-designed with parents, are now widely available across TVW for staff use (see resources). The 'Find -the- FiCare' game has been developed to aid with training local teams about FIC and staff can continue to use this resource on local teaching sessions. The 'Find -the- FiCare' game has now been adopted by several ODNs nationally as part of their FIC training resources. CCs, local AHPs and Psychologists are working closely to develop FIC teams in all units to assist with training and embedding FIC practices. This ensures parents/carers receive equitable care as they travel across TVW, receiving care closer to home when appropriate. Feedback from those units who have implemented this resource has been positive and staff have liked its interactivity. The CCs are supporting the local teams in its use. The resource can be found on the ODN website: [Find the FI Care](#)

This will be achieved by the ODN MDT delivering teaching at unit level as well as ODN specific study days, helping to support the practice educators and FiCare Leads to embed FIC Training sustainably and continually throughout the year. The aim would be to work with the Practice Educators and FiCare Leads to ensure FIC training is part of yearly Statutory and Mandatory education, required to be completed by all staff, either digitally or in person. FIC teaching is embedded in the QIS Foundation and QIS Specialist programmes and facilitated by CCs and AHPs and Psychologists.

#### Prem Kumari Chapagain - FIC Lead in Reading

Prem is enjoying her FIC Lead role and always looks forward to learning the new skills needed for this role. She feels her biggest achievement since starting her role is Parent Led Tube feeding. Previously parents were not encouraged to tube feed their baby/s. Since their change of practice, the feedback from parents has been incredibly positive, saying 'they are feeling more involved in their baby/s care.'

Prem works closely with the education team on the unit, providing teaching sessions for new starters on BFI Neonatal standards. She has also been able to educate staff and student nurses / student midwives in small teaching sessions at the cot side, about the principles of FIC, ensuring that parents are being supported to be partners in their baby's care.

Prem is working collaboratively with AHPs on the unit, ensuring that parents are encouraged, motivated, supported and included in the decision-making processes in their baby's care. Also promptly referring parents to the clinical psychologist for emotional support should the parents wish to be.

The team are starting a new project to encourage and support parents to take their baby's temperature and re-site saturation probes.

The team were only providing food for the parents who are resident in the flat, but recently, lunch boxes for the parents who spend a day in the unit are being provided so parents do not need to leave the unit for lunch if they do not wish to.

In Dorchester during QI project week (September) we had a display for Neonatal Nurses week which showed all the QI projects the neonatal nursing team had contributed to such as improved admission and discharge checklists, feeding our families and preterm optimisation. Following on from this we were asked to present to the Joint Transformation Board for DCH and UHD about how our families benefit from our unit ethos of adopting a culture of continuous improvement. We talked about how everyone in our team contributes to change and improvement and how our unit has a culture of inclusive learning for staff, students and parents. The board were interested to know what we do to keep our families together where possible, and how having a Family Integrated Care Lead and other quality roles facilitate this and other provisions. They really enjoyed seeing improvements like our unit tour and journey cards and seeing real feedback from families that have had experience of our Special Care Baby Unit.  
Jeny Hyett, FIC Lead in Dorchester

### **What do the FIC Lead Nurses need to succeed.**

This is what the FIC Leads have suggested that they need to make the role sustainable and achieve the embedding of FiCare on their units.

“I think it is about time and protecting the hours whenever possible. For most this means not being pulled clinically, for me it has been covering ward manager responsibilities which are a totally different set of skills/knowledge.

I think recognition that if/when this is the reality, then the FIC work is compromised and either inconsistent or unachievable as no one does this for us when we cannot do it.

Time to deliver training, to listen and support families, to develop resources and time to collaborate with others e.g. AHP’s. Time to get supervision/peer support and work with care coordinators and the ODN groups.

Exploring what leaders know about co-production and the whole cycle that starts with capturing patient experience that is not just a tick box exercise. Thinking about how this celebrated, shared and used for improvement. How leaders can support this on their units”.

## 6.2 UNICEF Baby Friendly Initiative (BFI) funding & BLISS Accreditation: Key to Partnership Empowerment Wellbeing Culture Environment

All 14 units in TVW have received funding for training the trainer to attain level 3, full accreditation with UNICEF Baby Friendly Initiative (BFI): Challenges remain where units do not have funded Infant Feeding Leads to facilitate the training in a timely and consistent manner.

Unit	Baby Friendly Initiative Stage 2024
Basingstoke	Stage 1
Chichester	Intent registered
Dorchester	Intent registered
Isle of Wight	Stage 1
Milton Keynes	Stage 2
Oxford	Full accreditation
Poole	Intent registered
Portsmouth	Stage 2, working toward stage 3
Reading	Intent registered
Salisbury	Stage 3
Southampton	Stage 1
Stoke Mandeville	Stage 2
Wexham Park	Stage 1
Winchester	Stage 1

## **Bliss Accreditation Current Status January 2025**

[Bliss Baby Charter](#) | [Bliss](#)

### Costing

Pledge £300 – indefinite

Bronze £600 – indefinite

Silver £900 – 90% across the board, 3 years re audit

Gold £1800 – 90% across the board, 3 years re audit

Platinum £2000 – 90% across board, 3 years re audit

<b>Unit</b>	<b>Bliss Baby Charter Accreditation</b>
Basingstoke	Pledged
Chichester	Gold, year 2 review completed
Dorchester	Pledged
Isle of Wight	Pledge, pre charging model
Milton Keynes	Bronze. Silver audit submitted, resubmission awaiting
Oxford	Bronze
Poole	Bronze
Portsmouth	Platinum and working on platinum reaccreditation
Reading	Bronze
Salisbury	Pledge, pre charging model. FIC lead is communicating with Bliss
Southampton	Gold - expired 2019. Unit recently contacted BLISS re accreditation.
Stoke Mandeville	Bronze
Wexham Park	Bronze. Payment made to move to Silver
Winchester	Pledge

TVW are also supporting those units who wish to work towards BLISS Baby Charter Accreditation, this is currently funded at local level if the decision by the unit is to proceed on the accreditation pathway. Due to the costs involved in achieving the 4 levels of accreditation, TVW has chosen to utilise available funding to support BFI accreditation for neonatal units who did not have access to additional external funding.

FIC teams and CCs are also looking at parental accommodation locally to review what might be possible within the current footprint of the units and what alternative might be available to them to explore. An example of this is the new Woodland Ward, Special Care unit (SCU) in Southampton, where the focus is FIC. Parents/carers will have the option to sleep next to or close to their babies, on pull down beds at the cot side, be invited to be present for ward rounds and be involved in all aspects of the planning and implementation of their baby's care.

### 6.3 Repatriation: Key to Partnership Empowerment Wellbeing

The TVW Repatriation Framework (see resources) and the introduction of the Link Nurse role has empowered parents to become actively involved with the planning and preparation of repatriating their baby back to their local unit. It has also supported staff with the transition of families ensuring that they have the appropriate support on the parents'/carers' return and that relationships have been formed through the Link Nurse to ease the transition for families and staff. This has supported the mental health and wellbeing of families. As part of the Repatriation Workstream, the Repatriation guideline was reviewed and updated. A Repatriation Video 'Moving Closer to Home' produced with parents and VCreate is now being viewed worldwide. This resource enables families to fully understand being repatriated to their local units for ongoing care and their part in the planning of that move. [Transfer Closer to Home: The neonatal repatriation of your baby - YouTube](#) We would ask that this is shared with all families when they are not local to the unit in which they are receiving care. This should be shared early on so parents/carers can prepare mentally for repatriation back to their local units as their baby's progress allows. This video was co-produced with the PAG, and their stories formed its narrative.

The role of the Repatriation Link Nurse was developed as part of this workstream to support outlying families throughout their neonatal journey, from antenatal transfer and admission to tertiary centres. PAG members shared how stressful the move to another unit was and how ill-prepared they felt for the transition closer to home.

#### Parent Quote from the video

"At first, we were surprised when the possibility of repatriating our baby came up after 2 months on NICU, we were concerned we would not receive the same level of care but understanding this was a move in the right direction and that our baby was improving and needed less intensive care, really helped us come to terms with the change."

The Link Nurse builds and maintains relationships with these families acting as a liaison between them and the neonatal units where they receive care. As an information point and advocate for families, the Link Nurse helps, signposts, and supports them through various stages of their journey.

**Parent Quote from the Repatriation video**

“When we were moving to a new unit, I was expressing and worried whether I would be able to carry on. It was knowing the little things like where the expressing rooms are, where the accommodation is and how much the car park costs, that helped reassure me and made me feel more grounded and in control.”

One of the key responsibilities of the Link Nurse is to initiate conversations with admitting units about timely repatriations closer to home, helping families prepare for this transition. Currently, nine units within TVW have allocated Link Nurses, with the remaining five units preparing to fill these positions.

Feedback from families has been overwhelmingly positive, with many expressing that the Link Nurse role is invaluable in helping them prepare mentally and physically for their move to a local unit.

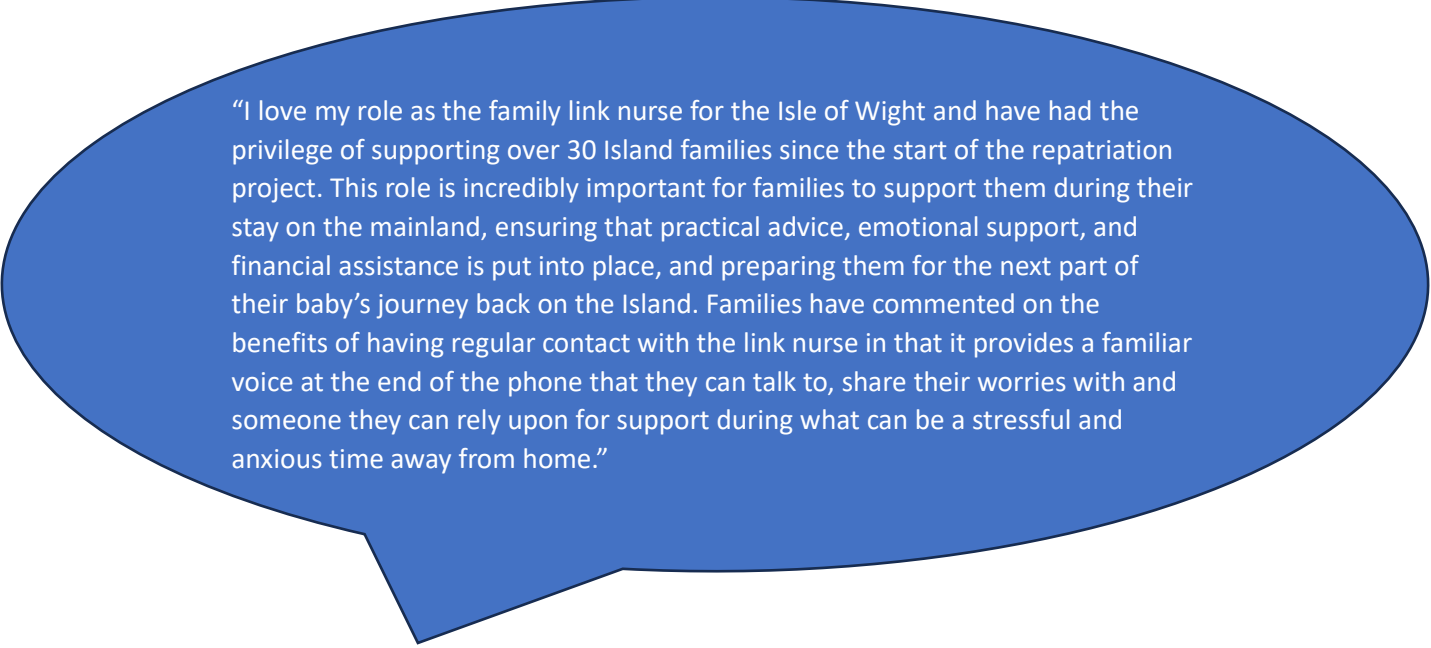
Lorna is mum to two boys both born at 23 weeks gestation, ‘H’ in 2019 and ‘A’ in 2024. When I met with her, she was able to reflect on the differences between the two experiences not in medical care, but the care and support that both she and her husband had received.

Gill Pears as Link Nurse was pivotal in that.

Lorna felt that they were very much kept in the loop with plans for ‘A’s care and were involved in the decision making but most of all their preparation for their move back to the Island was amazing. Lorna felt that the local team knew all about ‘A’ and his journey in the NICU and having that early relationship with Gill had been invaluable. They felt so much more confident in coming back to the Island and continuing ‘A’s’ care and planning for discharge home. The support the team also gave to older brother ‘H’ was incredible and he settled back into the local unit and the new routine, so well.

**Gill Pears. Link Nurse for the Isle of Wight**

Gill Pears was one of our first Link Nurses and has led the way developing the role and supporting others as they have come into post. This is her own feedback on her role:



“I love my role as the family link nurse for the Isle of Wight and have had the privilege of supporting over 30 Island families since the start of the repatriation project. This role is incredibly important for families to support them during their stay on the mainland, ensuring that practical advice, emotional support, and financial assistance is put into place, and preparing them for the next part of their baby’s journey back on the Island. Families have commented on the benefits of having regular contact with the link nurse in that it provides a familiar voice at the end of the phone that they can talk to, share their worries with and someone they can rely upon for support during what can be a stressful and anxious time away from home.”

## Jackie Warren George – Link Nurse in DCH

Jackie, a Band 6 Sister on the neonatal unit at Dorset County Hospital in Dorchester, took on the role of Repatriation Link Nurse in 2023. This is currently an unfunded role that she performs alongside her clinical duties. Dorset County Hospital has a Special Care Unit that cares for babies from 32 weeks of gestation. Those requiring intensive or high-dependency care are transferred either in utero or ex-utero once born. Between April 2023 and April 2024, 25 babies were born in tertiary centres and 20 babies were transferred following birth. The unit often struggled to stay updated with the progress of these babies, delaying their repatriation to Dorchester, and keeping them further from home longer than needed.

The benefits of the Link Nurse role include:

- **Early Contact with Parents:** Reassuring parents that the unit is aware of them and are in discussions with the team at the tertiary unit. This reassures parents that their baby will be repatriated as soon as they are declared stable and well enough.
- **Addressing Parent Needs:** Identifying and addressing any needs the parents may have, such as financial worries and mental health concerns. For example, the unit may be able to help with transport funding and provide frequent telephone calls and visits to ease parents' worries.
- **Consistent Communication:** Keeping detailed records in the handover file to ensure all staff are aware of outliers and receive regular updates, helping them to get to know families before they return.
- **Prompt Repatriation:** Establishing early contact with tertiary units, which has improved the timeliness of repatriations, allowing babies to return to Dorchester promptly.

Feedback from families has highlighted the invaluable role of the Link Nurse in preparing them mentally and physically for the move to their local unit.

## Case Study

Baby A. Born at Portsmouth Hospital at 25+5 weeks gestation and requiring intensive care. Parents were both 19 years old. I contacted parents early on and reassured them they would return to us as soon as he was clinically stable and well enough. I stayed in close contact with parents and staff on the unit. It was clear that it was a tough journey for parents. They were quite young and very isolated being away from home and their families. Dad was driving a considerable distance to work having to leave Portsmouth at 04.30 am every day. Baby A had a lot of difficulties and both parents coped tremendously well with what must have been a huge impact on them, mentally, physically, emotionally, and financially. Getting them home was a priority. We managed to get them straight back to us at less than 32 weeks. They stayed on our unit in one of our parents' rooms enabling them to get to know their baby and take on all his cares and feeds. They thrived during their time with us, and baby A was discharged home before his due date.

## 6.4 Journey Cards: Key to Partnership Empowerment

In line with the NCCR Transformation Plan, TVW and the PAG have developed a Parent Passport which are called Neonatal Journey cards. Parents/carers will be offered an initial admission pack of cards which they can build on as they feel ready to learn new skills in caring for their baby. These cards will be standardised across TVW, so parents/carers can continue to build their journey cards as they move across the Network. The cards and the learning parents have completed will be honoured and respected by all units as they journey through neonatal care across TVW region.



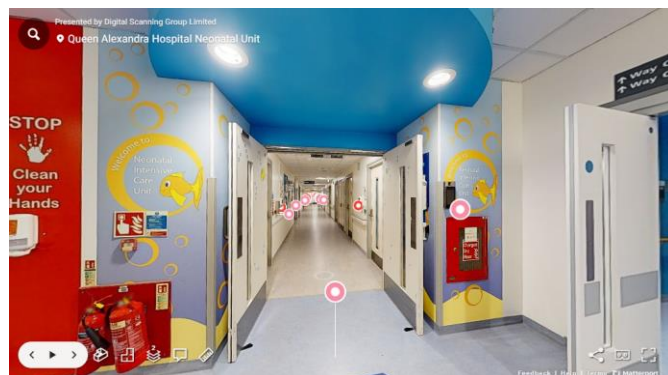
These cards have been jointly developed with Kent, Surrey, Sussex Neonatal ODN, and the cards will be transferable across the Southeast Neonatal Region.

Using the Parent Journey cards is vital to help parents/carers to learn the skills needed to care for their baby and to be able to actively participate in all areas of care when they feel ready. Staff can listen to what parents/carers feel they need and support them to become the parents they want to be for their baby when they feel ready. Staff can guide parents/carers in what they can do for their baby and help them to feel partners in the care of their baby, not bystanders just observing. These cards have been funded by the ODN for 1 year and we are working to ensure that these remain cost effective and sustainable, ensuring units can embed their purchase into their business cases for subsequent years.

## 6.5 Parent/carer Digital Resources: Key to Partnership Empowerment

### 6.5.1 3D Neonatal Unit virtual Tours

TVW ODN has supported and funded the creation of 3D virtual tours of all 14 Neonatal Units for parents and families to access. The tours provide an excellent opportunity for families to virtually 'walk the ward' on a digital device. The user can self-navigate or click on the play button for an easy 3D tour experience. Information tags have been added to explain the different areas of the neonatal unit and the equipment, this enables families to familiarise themselves with the clinical area and gain valuable information about their stay. Digitalisation of



information for parents/carers is a priority to ensure ease of access for families. The ability to access this digital information can be particularly useful during preparation for repatriation, as a resource for family members who are unable to visit in person, and as a tool for familiarisation during the antenatal period.

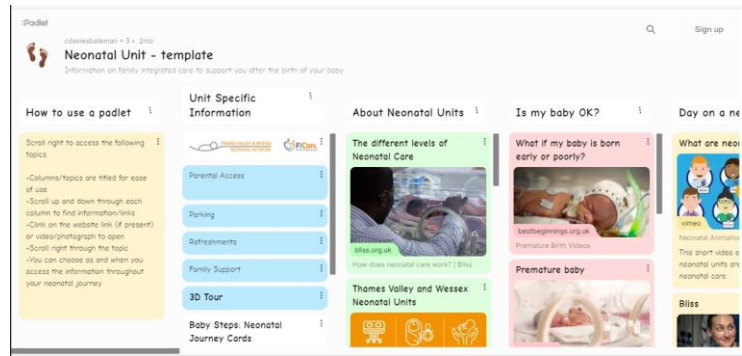
The only recurring cost for each unit once the initial 3D footage is captured is £55 per year to access the digital data. These tours can be accessed via hand held devices or online via computer.

Links to individual unit 3D tours and available here: [Unit Information](#)

## 6.5.2 Padlets

TVW ODN is supporting local units to design Padlets to hold local and national information for families to access.

Digital education platforms have been developed, and after discussions with the Parent Advisory Group, it was agreed that this type of resource would be highly beneficial to parents requiring neonatal care.



Each Padlet includes generic information that parents and families may need during their neonatal journey, as well as unit-specific details such as accommodation, 3D tours, parking, and available facilities. Padlets can be translated into multiple languages, enhancing accessibility for all families. This resource is cost-effective, as it is free to use, and it helps reduce the reliance on paper leaflets in neonatal units. The platform will help standardise information delivery to parents across the Network, aiming to reduce the conflicting advice experienced by parents as they move between different units within the ODN.

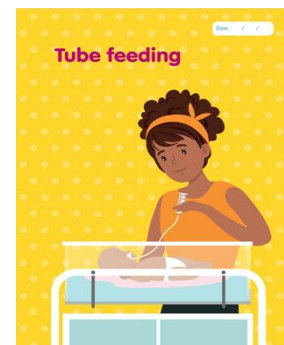
The SE Neonatal ODNs website holds much information for parents/carers to access.

<https://neonatalnetworksoutheast.nhs.uk>

## 6.6 Parent Tube Feeding Training Package: Key to Partnership Empowerment Wellbeing

The driver for this initiative was feedback from the PAG indicating inconsistencies in providers across TVW in training and facilitating parent/carer led tube feeding for their babies, leading to variations in their ability to care for their babies as they moved across the network.

In response, a training package was designed with input from families and launched in 2023. 13 of 14 units in TVW have agreed to adopt its use and will honour any training commenced or completed in another unit. The Care Coordinators are teaching staff how to use this resource with families and encouraging them to introduce the concept during initial conversations when tube feeding is first started, regardless of the baby's gestation or the amount offered. There is an accompanying Tube Feeding Journey card, which parents can use when they feel ready to learn this skill.



**Tube Feeding Your Baby on the Neonatal Unit**



Parent/Carer Learning Pack

Baby(s) Name: \_\_\_\_\_  
 Parent/Carer Name: \_\_\_\_\_

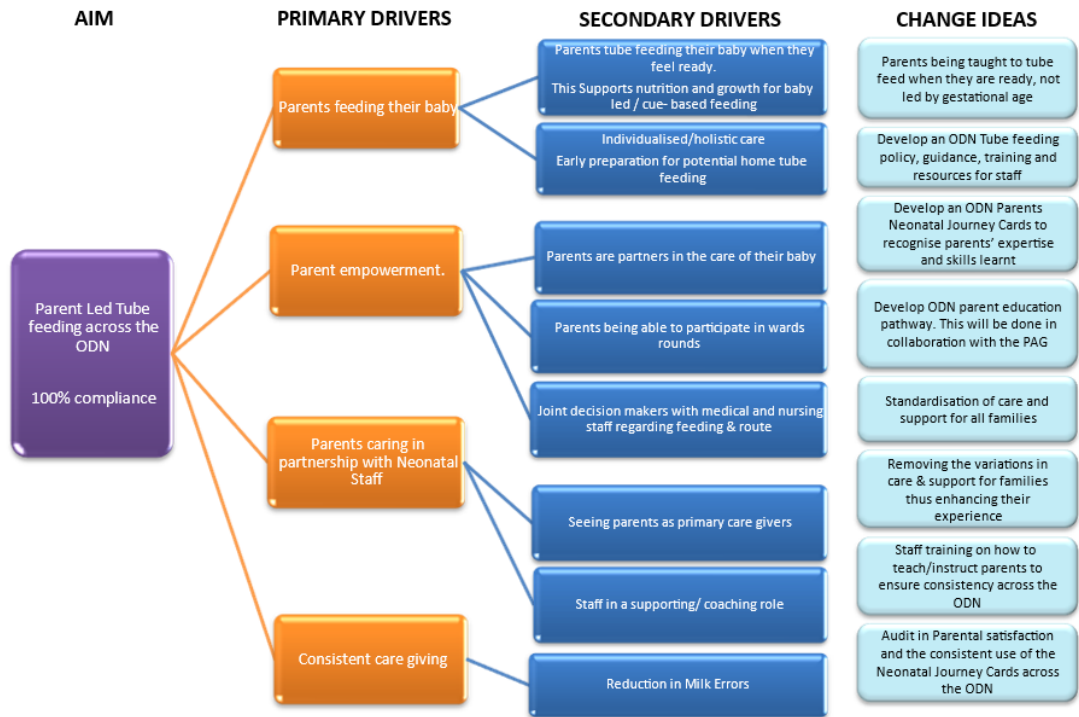
Parents/carers, being able to feed their baby is a fundamental aspect of caring for their child. They should always be invited to be present at the first feeding, even if it is a small trophic feed. The first feed is a major milestone for all parents, regardless of their baby's age or gestation.

When parents/carers feel ready to learn how to feed their baby, healthcare teams should support them using the Parent-Led Training Package. Parents/carers should be actively involved in learning care skills rather than merely observing. With the guidance and mentorship of staff, they can develop these essential caregiving skills.

Active involvement in feeding contributes significantly to parents/carers mental health and well-being. By taking part in their baby's care, parents/carers feel empowered, valued, and recognized as partners in collaboration with medical and nursing teams.

Parents/carers play a continuous role in their baby's care, allowing them to observe, share and track trends in their baby's condition and progress over time.

**Driver Diagram for Parent Led Tube Feeding**



[TVW-NGT-feeding-guideline-v1-ratified-March-24.pdf](#)  
[Tube Feeding Learning Pack March 2023](#)

## 6.7 The role of Allied Health Professionals (AHPs) in Family Integrated Care: Key to Partnership Empowerment Wellbeing Culture Environment

AHPs (Physio, OT, SALT, Dietician) play a crucial role in supporting FIC in the neonatal unit. Their contributions are multifaceted and essential to the success of this approach. Here is how they contribute:

### 6.71 1. Empowerment of Families

- **Building parental confidence:** AHPs such as Occupational Therapists, Physiotherapists, Speech and Language Therapist, and Dieticians actively coach parents/carers to provide as much direct care for their babies as possible. They provide support and advice around parenting roles e.g. positive touch, handling, positioning, feeding and skin to skin, utilising developmentally appropriate strategies to protect their baby's neurodevelopment and build confidence.
- **Shared decision making:** They collaborate with parents/carers to gain an understanding of what is important to them in caring for their individual baby's needs. They support parents to advocate for their baby and communicate this with the wider neonatal team through ward round attendance, MDT meetings and by providing individualised care plans for families.

### 6.72 2. Education and Training

- **Staff training:** They deliver education and training for the neonatal team on different aspects of FIC and Developmental Care strategies through staff induction, mandatory training, QIS Foundation and QIS Specialist programmes and cot side teaching. They also support staff to recognise how FIC principles thread through all their care and decision making rather than viewing FIC as an optional extra.
- **Parent education:** They promote parental/carer confidence through cot side teaching, provision of universal resources, e.g. information leaflets and training videos, as well as facilitating parent groups and coffee mornings.
- **Environmental adaptation:** They provide advice around ensuring an optimal environment for both baby and parents/carers, e.g. provision of positioning equipment to support self-regulation and postural development for baby, ensuring the physical and sensory environment is appropriate for families and their baby.

### 6.73 3. Psychosocial Support

- **Emotional Support:** Psychologists and AHPs offer emotional and psychological support to families, helping them cope with the stress and emotional challenges associated with learning to parent, in the high-stress environment of a neonatal unit.

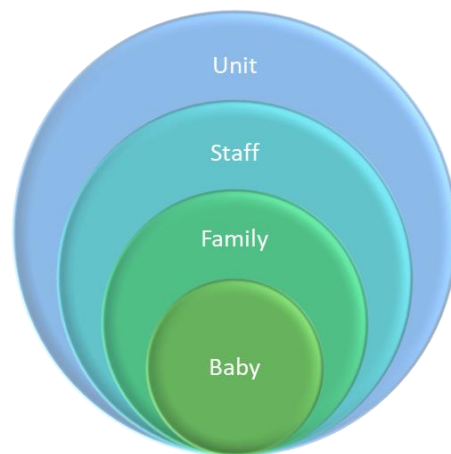
### 6.74 4. Enhancing neurodevelopmental outcomes

- **Holistic Care:** By placing parents at the heart of their baby's care, AHPs help to create a more holistic care environment that can lead to better patient outcomes, including

reduced length of stay, reduced stress for both patients and families, and a smoother transition from hospital to home care.

## 6.8 The Role of Neonatal Psychology in supporting FiCare: Key to Partnership Empowerment Wellbeing Culture Environment

Neonatal Psychological Professionals play a vital role in supporting babies, parents, and healthcare professionals within neonatal services. By integrating psychological expertise into the Family Integrated Care strategy, they help families navigate the emotional and psychological challenges of neonatal care while fostering a trauma-informed and supportive environment for babies, families, and staff.



Below, the contributions of neonatal psychology are outlined under the five key principles of the BAPM FiCare Framework. However, while significant progress has been made in increasing access to Psychological Professionals across Thames Valley and Wessex (TVW) neonatal units, some units still lack dedicated support. Even in units with psychology provision, staffing levels remain at 50% or less of national standards. In these cases, services must be carefully prioritised, meaning not all aspects of the support outlined below are currently available. With continued investment, the goal is to expand these essential services further.

### 1. Partnership with Families

- Neonatal Psychological Professionals support collaborative decision-making, ensuring parents feel heard and valued as key members of their baby's care team. They help parents advocate for themselves and navigate difficult choices, such as treatment options or palliative care, by providing emotional support and clear, balanced information.
- They provide guidance and training for staff on compassionate, trauma-informed communication, helping staff support parents in understanding medical complexities and feeling more involved in their baby's care.

- They work to strengthen relationships between families and neonatal staff, fostering trust and reducing stress.

## **2. Empowerment**

- Psychological Professionals deliver evidence-based interventions to help families cope with the emotional challenges of having a baby in neonatal care.
- They provide psychoeducation to help parents adjust to the neonatal unit, empathetically normalising their emotional responses to a highly stressful and often unexpected situation.
- They develop educational resources for parents and offer interventions to support infant-parent attachment and bonding, ensuring parents feel confident in caring for their baby and transitioning home.

## **3. Well-Being**

- Neonatal Psychological Professionals assess parental mental health and provide a range of interventions to support those experiencing anxiety, depression, PTSD, or grief.
- They also focus on staff well-being by offering training and structured support, including clinical supervision, reflective practice, post-event team reflections (PETRs), one-to-one support, and signposting to further resources.

## **4. Culture**

- Psychological Professionals play a key role in embedding a family-centred culture, ensuring neonatal teams adopt compassionate, psychologically informed care practices.
- They train staff to recognise and respond to parental distress and trauma, promoting a culture of compassion and empathy. They also provide support and consultation in cases of conflict, working proactively to reduce tensions through psychological formulation and effective communication strategies.
- They contribute to service development and policy, advocating for the prioritisation of infant mental health, a baby's developmental needs (attachment and neuroprotective care), and family well-being as fundamental aspects of neonatal care.

## **5. Environment**

- Psychological Professionals advocate for family-friendly neonatal spaces that support bonding and reduce stress.
- They work with teams to minimise barriers to parental involvement, such as anxiety about medical equipment or a lack of confidence in caregiving.
- They collaborate with neonatal units to provide tailored support for families with specific needs, including neurodivergence, learning difficulties, or pre-existing mental health conditions.

Neonatal Psychological Professionals play a vital role in supporting babies, families and staff within the FiCare framework, ensuring that emotional well-being is prioritised alongside medical care. Their involvement enhances family engagement, reduces psychological distress, and fosters a supportive neonatal culture that improves outcomes for both babies and parents.

### **What has been achieved within the last 3 years?**

In January 2022, NCCR funding enabled the establishment of a network lead psychology role to support the development of psychological care across the neonatal network. While this role was funded at a limited capacity, additional investment through the Ockenden review allowed for the expansion of local psychological provision within units across the system.

Together, these developments have strengthened the focus on family well-being and staff support across Thames Valley and Wessex Neonatal ODN. Key achievements over the past three years are outlined under the following headings:

### **Workforce Development**

- Authored and published national staffing standards for psychological professionals in neonatal care.
- Contributed to the BAPM service specification framework entry for psychological professionals and the Psychology section of the GIRFT review.
- Conducted unit visits, benchmarking, and developed a comprehensive gap analysis of psychological provision across the network, based on national staffing standards. Findings were shared with NHSE and the National Implementation Board (NIB).
- Responded to the Ockenden-linked funding call with a regional model of psychological support, developing a robust hub-and-spoke framework. This led to an increase in the psychology workforce from 2.5 WTE to 5.8 WTE, creating eight new part-time posts and increasing provision from 16% to 38% against national standards.
- Developed specialised job descriptions and person specifications and participated in recruitment and interview processes for new psychological professionals across TVW.
- Designed and delivered the online event *“Getting into Neonatal Psychology”* to raise awareness and support recruitment into newly created posts.

### **Education and Training**

- Led the development of the psychology curriculum for the now-published QIS (Qualified in Specialty) Standardisation.
- Created a training directory to promote psychologically informed thinking and practice within neonatal care.
- Secured HEE funding to design and author e-learning modules on neonatal psychology, accessible to all neonatal staff.
- Developed induction and CPD plans to support newly recruited psychological professionals entering neonatal services.

- Successfully bid for £6,000 of HEE funding to deliver TRiM (Trauma Risk Management) training and secured additional Ockenden underspend to extend access across units, supporting staff well-being and retention.
- Contributed psychological expertise to the design and delivery of the ODN's Leadership and Management Programme, embedding sessions on building Psychologically Informed Neonatal Teams.

### **Supporting Clinical Practice**

- Developed a rolling programme of professional meetings to support neonatal psychological professionals across TVW, enabling peer support, consistency of care, and shared learning.
- Created a Service Directory detailing psychological provision in each unit to aid appropriate and timely referrals for families.
- Designed the *Neonatal Psychology Padlet*, a centralised digital resource hub for staff and families: [Neonatal Psychology Padlet](#)
- Supported units in navigating and easing access restrictions that remained in place post-COVID in early 2022.
- Partnered with the KSS Lead Psychologist and Neonatal Care Coordinators to co-develop psychology-specific *Baby Journey Cards*, enhancing family communication and involvement.

### **Clinical Governance**

- Developed and implemented a minimum dataset for neonatal psychological professionals, capturing the impact of Ockenden-funded roles and collating outcomes annually to inform service development and evidence value.

## 6.9 The Role of the Network Pharmacist: Key to **Partnership Empowerment Culture**

Neonatal pharmacists are integral to the MDT, focussing on the optimisation of medicines for the individual baby and providing medicines education to both parents and staff.

### **Partnership: Parent Medication Administration Project**

A Network Lead Pharmacist was appointed in October 2024 and one of the projects being undertaken, in conjunction with the PAG, is to establish parents administering medicines to their baby in SCU'S and ensuring the PADDINGToN resources are used as a standard across the Network.

### **Empowerment**

Neonatal pharmacists work with other members of the MDT to build parents confidence in giving medication to their baby(s) by providing medicines information including how to give the medication, what the medication is for and importantly where to obtain further supplies and additional information. Parents should be signposted to the Paddington resources and Medicines for Children website for further reliable medicines information. It is crucial that parents are empowered to administer their baby's medication and that when they go home this is an everyday process with which they are comfortable with.

## Education and Training

In addition to providing parents with medicines information, neonatal pharmacists also provide staff training about medication and parenteral nutrition through local staff inductions, the QIS specialist programme and the Advanced Neonatal Nurse Practitioner training programme.

## Culture

Neonatal pharmacists contribute to the culture of the unit by promoting medicines related FI care. By implementing parent administration schemes, this will provide parents with time to practice and become confident in medication administration in a supportive environment. They will leave the units, having a clear understanding what each medicine is for, be familiar with how the medication is labelled and been able to ask questions and be signposted to additional information when they need it.

## 6.10 MDT Education: Key to Partnership Empowerment Wellbeing Culture

In alignment with the national QIS education standards, the Family Integrated Care model has been thoroughly embedded across the entire QIS programme. This integration extends beyond the delivery of training and education, encompassing the assessment strategies as well. An example of assessment could be the completion of an audit to measure the implementation of parent-led tube feeding within a specific unit. The vision outlined in the standards views FiCare as a "golden thread" that weaves throughout all Domains, seamlessly connecting key principles across the curriculum.

Practical examples of this integration are evident across the various domains. For example, in Domain 3 (Nutrition and Feeding), participants learn how to teach parents and carers to support tube feeding, while in Domain 5 (Neurodevelopmental Care), they learn how to mentor parents in developing skills to provide developmental care.

Newly qualified or those new to specialty—including Nurses, Midwives, Nursery Nurses, and Nursing Associates—will be introduced to the FiCare model through the Foundation QIS programme. This programme is also open to students, AHPs, psychologists, and pharmacists new to neonatal care. The objective is to equip them with a solid understanding of how to apply FiCare principles across all facets of neonatal care, with an emphasis on involving families and carers as active partners within the care team.

In the Specialist phase of the QIS programme, FiCare is revisited with a focus on intensive care, from the moment of admission, and through the neurodevelopmental care lens. This phase includes interactive learning, where participants are encouraged to share their experiences and explore strategies to enhance their application of the FiCare model.

FiCare training is led by neonatal professionals with expertise in the subject, ensuring high-quality, evidence-based delivery. In future, it is envisioned that future educational programmes will continue to incorporate this ethos, further embedding FiCare into the culture of neonatal care. All neonatal staff should receive training.

## 6.11 Outreach/ Transitional Care supporting FIC: Key to Partnership Empowerment Wellbeing Culture Environment

Delivering care at home, when possible, is an optimum level of delivering family integrated care. The parents/carers are the primary caregivers for 24 hours a day, 7 days a week. The family are empowered and given the knowledge and skills to care for themselves and their baby. Community professionals and/or outreach staff will support the family in their own home environment, and this is tailored to each family's needs.

Starting October 2023, TVW ODN commenced a scoping project on neonatal outreach services. 7 out of 14 neonatal units had some form of specialist support from a neonatal outreach team and practices varied across the region. We are striving to make this more accessible and equitable to all our families. The project lead for neonatal outreach is working with BAPM to develop National Standards for neonatal outreach. These standards will help us to review our patient pathways, commissioning, and models of care in TVW to facilitate earlier transition from the neonatal unit to home. TVW have also collaborated with KSS ODN to form a neonatal outreach group to share and benchmark practice as well as offer peer supervision.

In some areas of our region, multi-disciplinary neonatal outreach teams are empowering and supporting families to care for their babies and delivering some hospital at home programmes. These programmes substitute hospital care and facilitate earlier discharge home (including home nasogastric tube feeding) or are hospital prevention programmes (including home phototherapy). We will continue to support and facilitate safe, high quality, and innovative home care practices and support families to transition to universal paediatric support services.

### Neonatal Transitional Care

Keeping mothers and babies together should be the cornerstone of newborn care. Neonatal Transitional Care (NTC) supports resident mothers as primary care providers for their babies with care requirements more than normal newborn care, but who do not require to be in a neonatal unit (NNU).

Implementation of NTC has the potential to prevent thousands of admissions annually to UK neonatal units, and to provide additional support for small and/or late preterm babies and their families. NTC also helps to ensure a smooth transition to discharge home from the neonatal unit for sick or preterm babies who have spent time in a neonatal unit, often at some considerable distance from home. (BAPM 2017)

TVW has scoped the provision of TC across the Network and found that the models of care, staffing, location, and training for staff varies hugely.

The Network aims to work with local providers to establish safe and standardised care, to ensure that mothers and babies are not unnecessarily separated when babies have additional care needs that do not require admission to a neonatal unit. This is in line with the 3-year

Delivery Plan for Maternity and Neonatal Services (2023) and measured through the ATAIN programme, recording avoidable term admissions to neonatal units.

Separation of mother and baby disrupts bonding and the establishment of feeding, which is crucial in the early postnatal period. (Battersby et al 2017) NHSE have identified that over 20% of admissions of term babies to neonatal units could be avoided and are working with maternity and neonatal services on the provision of services that keep mother and baby together thus reducing the risk of harm caused by separation. Evidence shows the lasting effects on maternal mental health, breastfeeding and the long-term morbidity of both mother and baby when separated.

The TCU model used at Wexham Park Hospital is 8 years old and was built from the BAPM guidelines published in 2017 for Neonatal Transitional Care – A framework for Practice. The unit has 8 beds and is situated within the postnatal ward, and it is staffed by an experienced Midwife and a Band 3 Maternity support worker, both 5.4 whole time equivalents. Each of these Midwives are trained to be able take baby blood samples, insert NG tubes, give IV antibiotics as an example. The MSW's can calculate feeds, support NG feeding/Breast feeding and monitor jaundice and treat appropriately with the Midwife. The midwifery model allows sick mums to be cared for by the Midwife alongside their sick babies, thinking family rather than separate carers.

**Kindly Shared by Alex Buck. Wexham Park Hospital**

“Transitional Care at Southampton was first introduced in January 2019 to prevent the unnecessary separation of families and babies requiring ‘extra care’ as categorised in BAPM guidelines (2017). Staff with additional training and expertise provide care for these babies and support them to remain with their mother/carers as their primary carers, while they also receive the care they need. Since 2023 this now includes babies with NGT. It is delivered within the postnatal ward and although not a separate unit, where possible families requiring TC are cohorted together in designated bays or side rooms. It has the capacity to care for 6 babies, but this can be increased to 10 babies with additional staffing. Staffed by a midwife and a neonatal Band 4 nursery nurse/Associate practitioner, each baby also receives a medical review daily and Outreach involvement as required”.

**Nicky Ringrose. TCU Sister. Princess Anne Hospital, University Hospital Southampton**

## 6.12 Parent Advisory Group (PAG): Key to Partnership Empowerment Wellbeing Culture Environment

The group consists of parents/carers, and their families, who have experienced neonatal care in one (or more) of the 14 neonatal units across the TV&W Neonatal ODN, at some point in our lives.

The aim of the group is to ensure that parent voices are integral in shaping neonatal care services across TV&W Neonatal ODN.

The focus of the PAG is helping to improve the experiences of families on their journey through neonatal services now and in the future by working in collaboration with the Network teams and local providers, to ensure that the aims of the NCCR Transformation plans are met.

The PAG supports and promotes the development of FIC across the Network by:



[TVW Parent Advisory Group - Neonatal Network South East](#)

## 6.13 Palliative Care: Key to Partnership Empowerment Wellbeing Culture Environment

Most newborn babies cared for by perinatal teams survive. Advances in foetal and neonatal care mean that mortality rates in NICUs have decreased over the past two decades in high income countries like the UK. This is in line with the National ambition to reduce Neonatal death and brain injury by 50% by 2025.

[B1915-three-year-delivery-plan-for-maternity-and-neonatal-services-march-2023.pdf \(england.nhs.uk\)](#)

[NHS England » An update on delivery of the first year of the Maternity and neonatal three-year delivery plan and next steps](#)

However, the prevalence of children with life-limiting or life-threatening conditions has risen over recent years, with the largest increase seen in infants under the age of 1 year. New forms of diagnostic testing (such as genome sequencing and advanced imaging technologies before or after birth) are identifying a growing cohort of foetuses and babies with potentially life-limiting illness. Furthermore, success in acute stabilisation of critically ill newborns born extremely prematurely or with major congenital malformations can be followed by a long period when outcome is uncertain. Some such babies will die after a long period of intensive care whilst others will live with medical complexity and additional care needs linked to the underlying disease and its treatments. Owing to these factors, the number of babies who are now eligible for palliative care is increasing. It has been estimated that at least 2500 babies each year in England and Wales cared for in NICUs would benefit from palliative care (BAPM 2024).

TVW is committed to ensuring all families across the ODN receive equitable, high-quality palliative care delivered in the most appropriate setting and, if possible, closer to home. Collaborating with the Southampton Oxford Neonatal Transfer service (SONeT), TVW facilitates the repatriation of babies and families for palliation near their homes. TVW has a comprehensive Palliative Care Framework. We recommend the local teams work closely with the Paediatric Palliative Care teams and the third sector children's hospices, to ensure that all families are offered/ aware of, all the options available to them when needing to consider palliative/end of life care for their baby.

[Palliative Care - Neonatal Network Southeast \(neonatalnetworkssoutheast.nhs.uk\)](#)

The ODN has established a Palliative Care Special Interest Group (SIG), which meets bi-monthly and includes identified leads from all 14 units. This group shares expertise, case studies, and updates on national initiatives and legislative changes.

Currently, the Bereavement Lead posts are unfunded and are managed by staff, passionate about providing high-quality palliative care. In 2023-24, TVW facilitated six bereavement study days across the ODN, training over 200 staff members.

TVW staff are collaborating with a National SIG to develop the next quality roles for Neonatal Palliative Care Leads, aiming to align them with the funded Bereavement Midwife roles established across England. Presently, there are only 10 funded Provider Neonatal Bereavement Lead roles in England.

In Autumn 2024, TVW ODN joined the National Neonatal Palliative Care Programme, led by Alex Mancini, National Lead Nurse for Palliative Care. The aims of this project are:

- To reduce inefficiencies in delivering consistent high-quality neonatal palliative care and facilitate smooth care pathways for each baby and their family.
- To provide practical support for staff working across disciplines and develop robust working relationships across service boundaries to facilitate integrated care.

- To develop an equitable service across the region, empowering families to have choices regarding the care of their baby and enhancing the family experience (True Colours Trust Project 2023).

Neonatal staff will be invited to participate in monthly bite-sized training sessions (rolling programme) and enhanced days on specific topics related to the "Neonatal Palliative Care for Nurses" textbook. Two-hour virtual sessions will be held alongside e-learning modules and open discussions.

TVW ODN believes this initiative will help develop a skilled workforce to be confident and competent in delivering high-quality, equitable palliative care across the ODN, thus enhancing the parental journey through neonatal care in line with the NCCR Transformation Plan.

## 7.0 TVW ODN FIC Key Recommendations

The recommendations from TVW, ODN to achieve high quality, equitable FIC for families as they move across the ODN are:

### 7.1 Access to AHPPPs, Support & Guidance

#### **Developing Our Neonatal Workforce**

Within the ODN we are committed to supporting units to work towards meeting the staffing standards as set out in the BAPM Service Specification and within discipline specific standards. These can be found in the links below.

BAPM Service & Quality standards for Neonatal Provision in the UK:

[Service and Quality Standards for Provision of Neonatal Care in the UK | British Association of Perinatal Medicine](#)

[Neonatal Multi-Professional Team | British Association of Perinatal Medicine](#)

All units should have an awareness of whether they meet these standards and where not, and work with relevant workforce leads to build NHS trust level business cases to achieve them.

### 7.2 24- hour access to Parent accommodations

CC to support local teams with the preparation of business cases to support plans for future accommodation provision for families. Where the current geographical area of a unit does not allow for increasing accommodation, for teams to be creative in thinking of ways families can be closer to their baby. E.g. linking with local hotels/apartments or sharing accommodation with paediatrics.

For rooms not to be viewed as 'rooming in rooms' prior to discharge but for access to all families as they are available. No accommodation should be left empty.

All parents should be provided with a place to relax within the footprint of the unit, with access to comfortable chairs, food preparation, storage and eating areas, appropriately equipped.

### 7.3 24-hour access to food

All families must have access to food 24 hours per day. This is vital for the physical and mental wellbeing of the parents and ensuring mothers have enough nutrition to support breast feeding and healing.

### 7.4 Free parking in all units

All units should be able to offer discounted parking, if not free parking to all parents for the duration of their neonatal stay

### 7.5 Family rooms for parents & siblings

All units will have appropriate family facilities for both parents/carers and siblings to be able to spend time together as a family whilst their baby is receiving neonatal care.

### 7.6 Parent participation on ward rounds

Parents/cares should be actively involved in the ward round discussions and plans for their baby. They should be invited to be present and encouraged to participate in the conversations surrounding their baby's care. They should never be bystanders in a conversation involving their baby. Parents/carers will soon become the expert in their child, being the continuum and will be best placed to share what they have noticed and the trends they are observing. 'No decisions made about me without me.'

### 7.7 Open access for parents

All units must have open access for parents/carers and visiting access for siblings, extended family and /or close friends. Parents/carers know the support which best suits their needs and units should try to accommodate this whenever possible.

### 7.8 Support with travel expenses

We would wish for all units to be able to sign post parents/carers to support with travelling expenses. Hospital trusts may have systems in place to support families on lower incomes with claiming back travel costs.

## 7.9 Parent led tube feeding

As an ODN we are encouraging all our teams to support families to learn how to tube feed their baby when they feel ready. Please follow the ODN guidance on this and use the ODN training package so we can achieve consistency and equity for parents/carers across the Network. The CC are working with and supporting the local teams to ensure that these Training Packages are being used and shared across the Network.

[NGT Feeding - Neonatal Network Southeast \(neonatalnetworksoutheast.nhs.uk\)](https://neonatalnetworksoutheast.nhs.uk)

## 7.10 Access to expressing breast milk equipment

Parents/carers have a right to expect to be able to sit comfortably with their baby. Chairs are not a luxury or something that should be bought from Charity. These should be counted as essential equipment for all units as they would be on a general ward. Parents/carers should have easy access to breast pumps throughout their stay and for use at home. Portable breast pumps and expressing kits should be provided to all those mothers who require them.

## 7.11 Access to an Outreach Service and TCU

All babies are transitioned to the home environment as soon as safely possible.

All families have access to a neonatal outreach service to support the parents/carers being the primary caregivers. They receive support to navigate the transition to home and on to universal support services (from health visitor), or specialist paediatric teams (i.e. community paediatric nursing teams)

Local neonatal teams strive to meet the BAPM framework for Neonatal Outreach recommendations when published.

Scope all outreach across the Network against BAPM framework for outreach services.

Work alongside national team to improve equity of service for outreach for families.

Ensure outreach services are in line with parental needs.

To continue to work with local providers to establish safe and standardised care, to ensure that mothers and babies are not unnecessarily separated when babies have additional care needs that do not require admission to a neonatal unit.

## 7.12 FIC Education and Training

All neonatal staff should have access to regular FIC update training as part of their yearly Statutory and Mandatory training.

## 7.13 Parents being central to Co Production

Parent/carers must be central to the work in any QI projects, keeping the service user voice at the centre of all we do. We would strongly encourage all local teams to engage

local parents in any plans and projects they have, to ask parents/carers what they feel is needed and could be future projects for service development.

#### 7.14 Palliative Care

All families should be able to receive end of life care close to home where possible. This involves Advance Care Planning with families to ensure that all options are explored and offered to the family. The ODN is facilitating training to ensure staff feel confident and competent to deliver high quality care with the support of specialist Neonatal and Paediatric Palliative Care teams.

If a family is not able to move prior to their baby's death, teams must ensure that local teams are aware of these families and that local support and follow up is arranged for them, including communication with community teams supporting that family, i.e. midwives, GP, and Health Visitors.

#### 8.0 Conclusion

As part of the transformation of neonatal services all units in TVW are working towards a FIC model of service delivery to ensure that all families cared for across TVW, have equity and parity of high-quality FIC, neonatal care. All families should expect similar provisions as they move across the Network, to meet their baby's care needs in the most appropriate setting.

The TVW ODN team will support the local teams to implement the change in culture to ensure parents are seen as primary care givers and are involved in the planning and delivery of their baby's care.

This will be achieved by the Neonatal MDT's willingness to being open to change and supportive of the FIC principles and philosophy, working together and placing the baby and the family at the heart of neonatal care.

Empowering parents and carers to be included in all decisions made about their baby's care will not only be supporting the physical needs of both baby and family but the global development of the baby, and the overall mental health and wellbeing of the whole family.

The ODN is working to ensure all projects are cost-effectiveness and sustainable by exploring alternative funding streams, to ensure that these initiatives are widely accepted and supported by all units across the Network.

## Resources

**Find- the -FiCare Game Resource** [Find the FI Care - Neonatal Network South East](#)

**TVW ODN Repatriation Framework and Guideline** [Repatriation Framework and Guideline - Neonatal Network South East](#)

[Transfer Closer to Home: The neonatal repatriation of your baby](#)

**Neonatal Network website** [Home - Neonatal Network South East](#)

[NGT Feeding - Neonatal Network South East](#)

**PADDINGTON Study Resources.** [Giving medicines to babies – Medicines For Children](#)

[Tube Feeding Your Baby Parent Leaflet - Neonatal Network South East](#)

**3D Tours** [Unit Information - Neonatal Network South East](#)

[Psychologically-Informed Neonatal Care - elearning for healthcare](#)

**Psychology Padlet** [neonatalpsychology profile | Padlet](#)

## References

[Bliss Baby Charter | Bliss](#)

**Bliss** [What is FiCare? | Bliss](#)

**BLISS 2021 Locked out report** [Locked-out-the-impact-of-COVID-19-on-neonatal-care-final.pdf](#)

**Bliss New Research** [Bliss launches new research of South Asian communities in neonatal care | Bliss](#)

**BAPM FIC in practice 2021** [Family Integrated Care | British Association of Perinatal Medicine \(bapm.org\)](#)

**BAPM Palliative Care Framework 2024** [Palliative Care - A Framework for Clinical Practice in Perinatal Medicine \(2010\) | British Association of Perinatal Medicine](#)

**BAPM Recognising Uncertainty 2024** [Recognising uncertainty: an integrated framework for palliative care in perinatal medicine | British Association of Perinatal Medicine \(bapm.org\)](#)

**Parental impact during and after neonatal intensive care admission**

**Danielle Guez-Barber & Betsy Pilon (2024)**

<https://www.sciencedirect.com/science/article/abs/pii/S0146000524000600#:~:text=Family%20engagement%20should%20not%20be%20tokenized%20or%20a%20%E2%80%9Ccheckbox>

**Framework for Practice. Holistic feeding and nutritional management for the near term/term neonate, following Surgery (2024)** [Holistic feeding and nutritional management for the near term/term neonate, following bowel surgery | British Association of Perinatal Medicine](#)

[Framework-for-Practice\\_NNSIG-V7.pdf](#) (Page 6 are partners in care)

**Maternity and Neonatal Equity and Equality Action Plan** <https://bnssg.icb.nhs.uk/health-and-care/health-advice-and-support/maternity-services/maternity-and-neonatal-equity-and-equality-action-plan>

[NHS England » Implementing the Recommendations of the Neonatal Critical Care Transformation Review](#)

**NHS England Three Year Delivery Plan** [NHS England » Three-year delivery plan for maternity and neonatal services](#)

**NHS England Three Year Delivery Plan and Next Steps** [NHS England » An update on delivery of the first year of the Maternity and neonatal three-year delivery plan and next steps](#)

[OCKENDEN REPORT - FINAL](#)

**Term admissions to neonatal units in England: a role for transitional care? A retrospective cohort study.** [e016050.full.pdf](#)

**True colours Trust. NATIONAL Palliative care Programme** [The True Colours Trust | National Lead Nurse in Neonatal Palliative Care](#)

**TVW ODN Palliative Care Framework** [Palliative Care - Neonatal Network South East](#)