British Association of Perinatal Medicine

Family Integrated Care

A Framework for Practice

DRAFT FOR CONSULTATION

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Contents

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Introduction

This BAPM framework seeks to support the implementation of a model and philosophy of care within which parents are enabled to be primary caregivers to their infants in partnership with clinical teams.

This framework describes the model of Family Integrated Care (FICare) and provides a structure for implementation in UK neonatal units and networks.

By seeking to adopt this model throughout the development and delivery of care you can, as advocated by a UK veteran neonatal unit parent below;

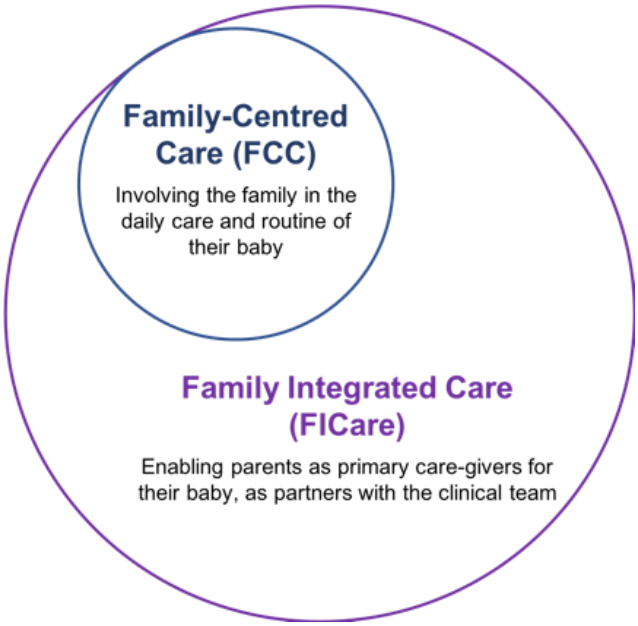
"Help us to help them be the best child they can be, by enabling us to be the best parents we can be from day one".

What is FICare?

Family Integrated Care (FICare) is a model of neonatal care which promotes a culture of partnership between families and staff; enabling and empowering parents to become confident, knowledgeable and independent primary caregivers. Neonatal units with a strong FICare philosophy nurture parents into this role by listening to them, building on their strengths and encouraging their participation in experiences and decision-making to enhance control and independence. The FICare model ensures that parents have the opportunity to be a family as soon as possible; creating space for necessary medical care whilst facilitating the nurturing bond and love that only parents can provide for their baby/babies.

FICare builds on the foundations of Family Centred Care (FCC), the core principles of which are defined in the Bliss Baby Charter [1] and supported by extensive research [2, 3]. FICare is a natural extension of FCC, progressing from parental involvement in care to supporting parents as equal partners in the care team and primary caregivers (Figure 1).

Figure 1: The relationship between Family Integrated Care and Family Centred Care



What FICare isn't?

FICare is not a single entity or tangible practice. Many individuals and neonatal units will already have embraced the underlying principles of FICare. However for FICare to be wholeheartedly embedded within a service, it requires a culture change away from the traditional model of neonatal care.

This paradigm shift in culture is often the most challenging aspect of introducing and maintaining FICare; everyone within the service, from the clinical leads and matrons to the housekeepers and porters, must be invested in recognising and respecting parents, as parents. This does not come from ticking boxes and investing in practical resources – it evolves from the FICare innovators supporting, educating and mentoring their team and leading by example. FICare at its fundamental base can be implemented for free, by a workforce invested in families as the essential core of their practice.

What is the rationale behind and evidence for FICare?

The FICare philosophy is inspired by innovative practice in resource-limited settings, where "care-by-parent" was a necessity associated with improved outcomes [4]. These pioneering models of care recognise that the well-being of mothers and infants are inter-dependent; and on a practical level ensure that parents can be with and care for their infant(s) continuously until discharge. Benefits of this approach include reduced mortality, reduced infection rates, reduced antibiotic usage, increased breast milk feeding, earlier discharge, reduced readmission and improved parental wellbeing (Appendix 1).

Shoo Lee and the team at the Mount Sinai Hospital, Toronto adapted these approaches to create the FICare model of "care by parent" for higher-resource settings [5]. Single centre cohort studies and multi-centre randomised controlled trials of this FICare model consistently demonstrate improved short-term outcomes for infants and their families [6, 7]. Importantly involving parents in care and decision making has been shown to promote bonding [8] and to enhance their confidence at discharge [9, 10] which have benefits for the longer-term outcomes of babies and families. FICare has benefits for neonatal staff too, empowering them to lead change in their unit and contributing to happy, cohesive teams [11]. A summary of the evidence in support of FICare is provided in Appendix 1 of this document.

What does FICare mean for families?

The impact of FICare on families is best articulated by parents in their own words…

"Our baby arrived 14 weeks early. She was so tiny, we were so scared. My husband and I didn't have a clue what to expect or what to do, she looked so fragile and had so many tubes and wires attached to her. The first few days were a bit of a haze, the NICU nurses took care of everything but as the days rolled by they encouraged us to get more involved with her cares and spoke to us about how we could connect with our baby girl even though she was in an incubator. It was a gentle, hands-on education - something we were scared to do – we always felt it best to leave it to the expert nurses - but they taught us to be the experts in caring for our precious baby with confidence…"

"Thanks to the FICare programme we soon stopped feeling helpless and instead felt really empowered. The team not only listened to us, they genuinely valued our input and observations of our baby girl to help tailor her care. By the time we transferred back to our local hospital we felt really positive and confident about caring for our baby- even the staff could tell there was something different about us!"

"Experiencing FiCare was as close to being home with our baby as possible. No-one plans to enter neonatal care. The sudden separation, daunting environment and worry for our twins was overwhelming. FiCare built a structure of care and inclusion for us as parents. It put family at the centre of care enabling us to be primary caregivers, just as we would be at home. FICare allowed us to develop our relationship with our baby and build the confidence to advocate for our baby's needs. We were simply a better family when treated as part of the medical team."

What does FICare mean for staff?

Feedback from staff, captured in the word cloud and quotes below, describes how FICare has benefitted and challenged the clinical team...

"Our unit has embraced the FiCare concept; it has challenged us as nurses to develop our roles from primary caregivers to understanding the important role that parents play in caring for their baby while in NICU."

"It is very much worth it - parents are much more confident - we don't get nearly as many phone calls from families after discharge."

"When you see parents doing what you have taught them; confident, empowered and educated - it is really worth it!"

How do neonatal units implement FICare?

Building on local foundations

Many UK neonatal units are already implementing a family integrated model of care, building on the well-established family centred approach supported by the Bliss Baby Charter [1]. Whilst the main principles of FICare are the same across all neonatal settings, the practical delivery of this model will look different in different units. Teams need to be flexible and adaptive to the resources available to them and the differing needs of individual families.

A new role for staff

One of the greatest challenges of FICare delivery is for staff to embrace new roles as mentors and supporters to parents, listening to each family to appreciate what really matters to them. Moving away from the traditional role of principal care provider may be challenging for staff and ensuring that they are educated and empowered to lead this change is essential to success.

Leading change together

Integrating parents as equal partners in the multidisciplinary team and engaging them in the decision-making process is a journey which can start with small steps, low costs and committed individuals. Feedback from units which have established successful FICare programmes consistently advocates a ground-up approach; empowering families and staff to develop ideas and lead change together. This model thrives in neonatal units which are reflective, innovative, resourceful and open to change and feedback from families; building the components of FICare that enable parents to deliver care as the primary caregivers to their baby/babies.

Utilising existing resources

In addition to the Bliss Baby Charter [1] there are several existing resources (summarised in Appendix 2) which neonatal units and networks can use to support the implementation of FICare.

COVID-19 and FICare

The COVID-19 pandemic has severely impacted delivery of FICare [12]. Infection control policies have prevented families from being present and involved in their babies' care, and restricted the support available from neonatal staff and extended family [13]. Health and wellbeing of infants, parents and neonatal staff have been at risk. These challenges have highlighted the critical importance of family involvement as a key component of neonatal care, which should be actively prioritised in national, regional and local remobilisation and recovery plans.

The UK Model of FICare

The UK model of FICare (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 FICare philosophy. These principles are based on the "pillars" of FICare first developed by O'Brien and colleagues at the Mount Sinai Hospital in Toronto [5], which inspired early FICare programmes in the UK and internationally.

Figure 2. The UK model of FICare

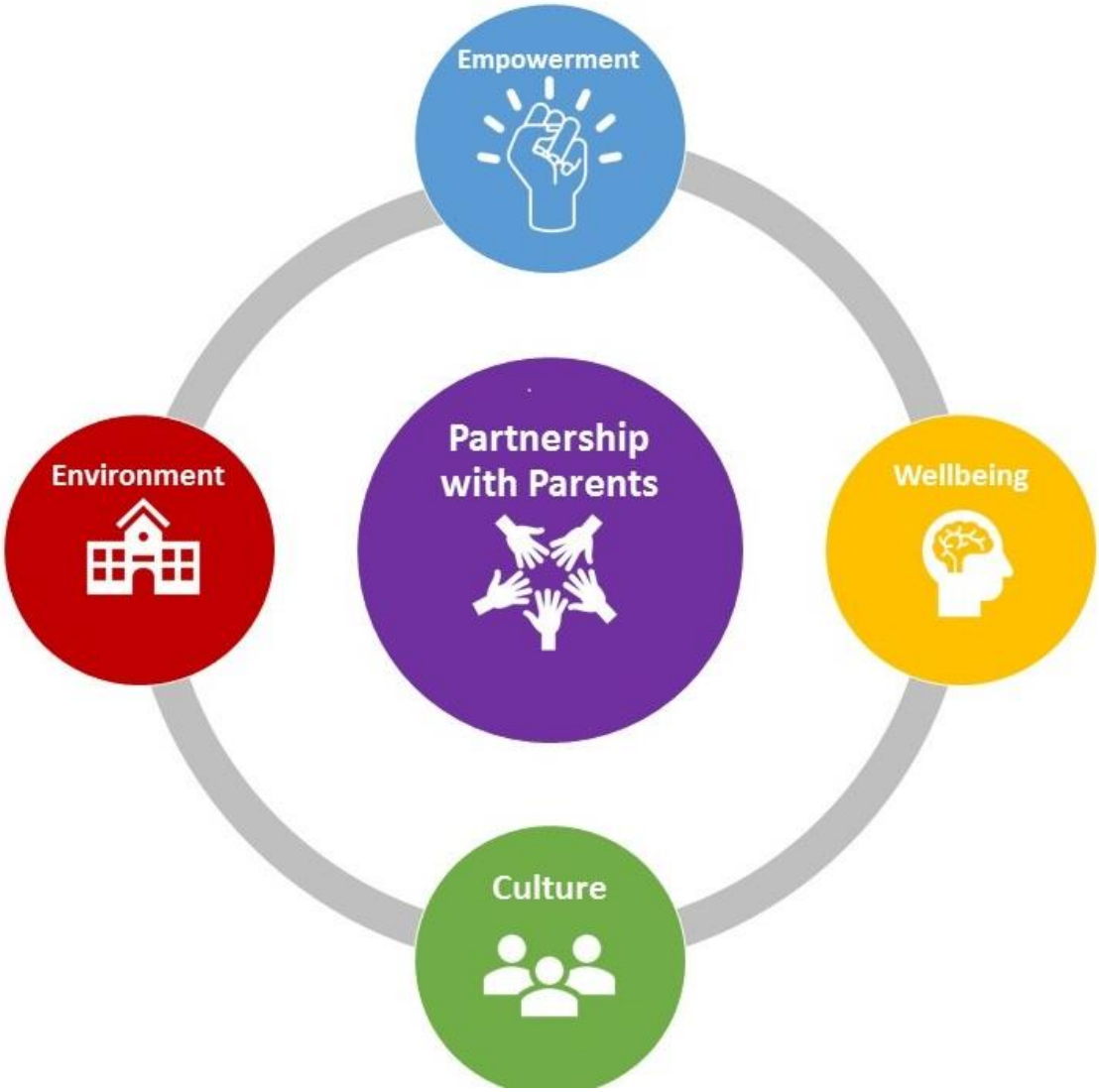
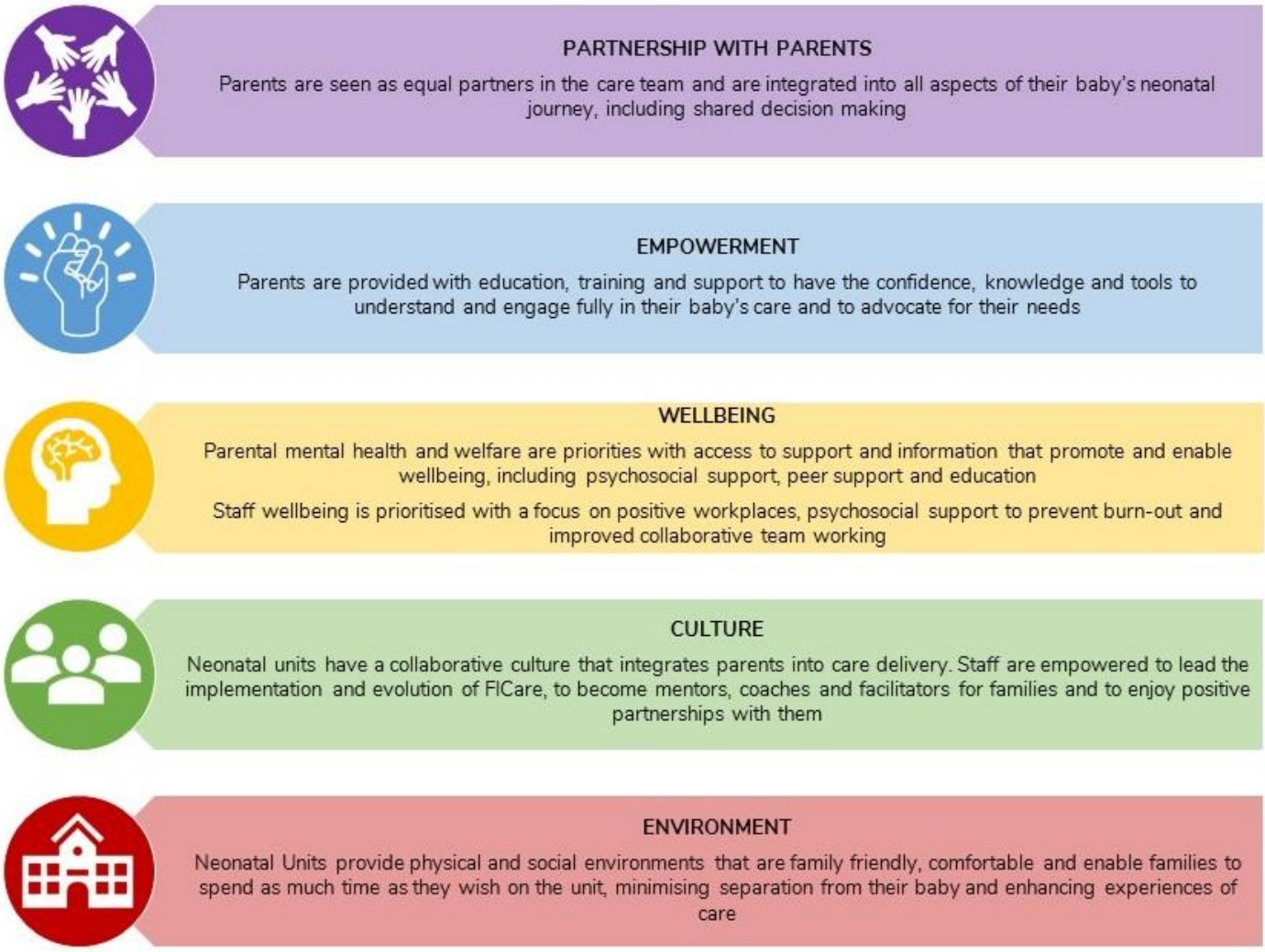


Figure 3. The five key principles of UK FICare



Key components of FICare on neonatal units

Each of the five FICare principles comprises several key components which if adopted and embedded will enable units to deliver care in partnership with families. Many units may well have a number of these components in place whilst others will require leadership and development at a local level. These components are set out in Figure 4 below. Practical examples of the successful implementation of the key components within each principle can be found in Appendix 3 of this document.

Figure 4. Key components of the five UK FICare principles

Partnership with Parents on Neonatal Units

- Positive partnerships are established with parents, supporting them to become involved in their baby's care as primary caregivers.
- From admission (or before if admission anticipated) parents are supported and encouraged to be comfortable providing care for their baby to the best of their ability.
- Parents are supported to be actively involved in ward rounds, daily care planning and decision-making.
- Parents have opportunities to give feedback about their baby's care while on the unit and after discharge.
- Parents' experiences and feedback are actively sought, to inform and improve the quality of services.
- Technology and innovations are used to support parental participation in care.
- Local FICare steering groups comprising parents and members of the multidisciplinary team are established to drive improvement.

Empowerment on Neonatal Units

- Parents are orientated to the neonatal unit environment before or on admission.
- Parents have access to information which outlines their role as parents and the philosophy of an integrated approach to delivering neonatal care.
- Ongoing orientation to support services available to parents during their stay.
- Provision of a structured education program for parents.
- Ongoing individual skills teaching and mentoring for parents at the cot side.
- Parent classes and activities offered at convenient times including out of hours, evenings and weekends.
- Opportunities are actively created for peer-to-peer learning.

Wellbeing on Neonatal Units

- Parents and staff have access to psychological support on neonatal units and after discharge.
- Regular unit and community-based opportunities for peer to peer support/parent group activities.
- Appropriate use of translation services to reduce the impact of language barriers.
- Inclusive and equitable access for all families regardless of age, disability, gender, race, religion or belief, sex and sexual orientation.
- Clear and consistent processes for ensuring parental access when transferring between units.
- Wellbeing activities are offered to all families (e.g. yoga, crafting, meditation) and staff.
- Links and support from local charities, organisations and community groups providing wellbeing support for families.

Culture on Neonatal Units

- Education and training activities for all team members on the philosophy and benefits of FICare and the expectations of their practice to support families.
- Education included in all staff orientation and annual skills updates.
- Mandatory staff training in communication skills, coaching and mentoring of parents.
- Training for staff in the provision of developmentally supportive care, neurodevelopmental care and trauma informed care.
- Identification of multidisciplinary FICare champions to support changes in practice.
- Engagement with parents in all aspects of the development and delivery of neonatal care locally.

Environment on Neonatal Units

- A welcoming and shared neonatal unit environment including; dedicated parent rest room, kitchen facilities for heating and storing food and personal storage space.
- 24-hour open access for parents and siblings to be with their babies.
- A comfortable cot-side environment with reclining chairs for rest and skin-to-skin contact, breast pumps and screens for privacy.
- A dedicated room for mothers to express breast milk in comfort.
- Proactive signposting of financial support for families including for travel costs, food and parking.
- Processes to enable smooth transition of care when babies and their families are transferred within and between units.
- Availability of on-site childcare/play therapists to support siblings.
- Access to dedicated neonatal parent accommodation for all those who need it.
- Rooming-in facilities for families to aid transition to home discharge.
- Dedicated rooms for families to stay with their baby during end-of-life care.

Implementing the FICare framework at neonatal network level

Neonatal networks have a key role in providing strategic leadership and coordination in the implementation of FICare within their region. The adoption of a regional approach or single network vision for FICare will have a number of direct benefits including to:

- Provide a clear structure and direction of travel for units in their region and the adoption and implementation of FICare
- Motivate and enthuse units about FICare
- Improve consistency and continuity of care across regional repatriation pathways
- Ensure families' experience of care is seamless and integrated
- Enhance collaboration and cooperation across units
- Ensure there is no duplication in effort or resources
- Ensure prioritising of national funding across a network

Key components of FICare within neonatal networks

Key components of network approaches to adopting FICare, aligned to the five FICare principles, are summarised in Figure 5. In addition, practical examples of the successful implementation of these key components can be found in Appendix 3 of this document.

Figure 5. Key components of neonatal network activity to support the five principles of UK FICare

Partnership with Parents in the Neonatal Network

- Regional commitment and leadership to support and value FICare
- Strong family and staff involvement in all aspects of development and delivery of neonatal care at a regional level
- Networks develop a regional FICare Framework

Empowerment in the Neonatal Network

- Access to neonatal unit virtual tours and single regional information portal e.g. website, social media
- Shared and consistent regional parent education resources
- Regional materials that support, educate and promote the philosophy of FICare e.g. animations, parent information leaflets
- Information for parents on neonatal care and regional pathways
- A rolling programme of regional parent education conferences
- Support for national campaigns and engagement with charities to ensure representation of the neonatal voice at a national level

Wellbeing in the Neonatal Network

- Development of a regional parent experience tool with regular feedback to neonatal teams
- Networks support and partner with charities/third sector organisations supporting neonatal care in their region to ensure equitable access to peer support/parent groups
- An inclusive approach to the implementation of the FICare framework for all regardless of age, disability, gender, race, religion or belief, sex and sexual orientation.
- Appointment of regional Care Coordinators to streamline an approach to FICare
- Development of regional pathways to access psychology support for parents and training to staff on the psychological needs of parents

Culture in the Neonatal Network

- Regional staff training resources, information and guidelines
- Support for regional innovations/QI projects that support FICare
- Inclusion of FICare into induction, QIS and training programmes for all staff groups involved in neonatal care including; nurses, doctors, allied health professionals, health visitors and early years providers
- Funded regional programmes which enhance skills and promote continuity and consistency across region e.g. FINE, Leadership Training, Coaching and Mentoring, baby massage
- A regionally agreed neonatal professional specification – outlining skills and characteristics required to develop FICare across regions
- An allied health professionals (AHP) strategy, setting out required AHP provision for the region

Environment on Neonatal Units

- Development of a regional parent accommodation strategy enabling adequate provision by 2025
- Transitional care in all units to minimise separation of mother and baby
- A regional strategy which identifies units which require re-design and expansion and support to obtain capital funding
- Regional procurement of equipment to support FiCare where appropriate
- Regional recognition of units achieving relevant accreditation and training programmes e.g. UNICEF, FINE, Bliss Baby Charter
- Clear and agreed paediatric transition pathways across region
- Biannual regional peer reviews against Quality Standards

Appendix 1. Summary of evidence in support of FICare

FICare effect on	Author and country of origin	Year of publication	Study design	Reported outcomes
Mortality	Mohan [14], India	1986	Prospective observational study of two groups	Reduced mortality (12.7% versus 33.1%)
	Karan [15], India	1983	Pre-post intervention study	Reduced mortality (5.5% versus 5.0%)
Infection	Mingyan [16], China	2020	Multicentre prospective cluster RCT	Reduced nosocomial infection rates in FICare group (4.13 versus 5.84 per 1000 hospital days; mean ratio 0.67, 95% CI 0.47-0.96)
	Levine [4], Estonia	1994	Prospective observational study	Reduced nosocomial infection
	Mohan [14], India	1986	Prospective observational study of two groups	Reduced mortality from neonatal sepsis (12% versus 34%)
Breastfeeding at discharge	Mingyan [16], China	2020	Multicentre prospective cluster RCT	Increased breastfeeding rates in FICare group (83% versus 71%) and breastfeeding duration (31 versus 19 days). At follow-up to 18 months, breastfeeding rates were significantly higher over time in the FICare group.
	Banerjee [7], UK	2019	Pre-post intervention study	Suck feeding achieved earlier and higher rates of both exclusive breastfeeding at discharge (68% versus 54%) and any maternal milk at discharge (95% versus 92%)
	O'Brien [6], Canada Australia, and New Zealand	2018	Multicentre prospective cluster RCT	High-frequency (≥6 times a day) exclusive breastmilk feeding rate at discharge was higher for infants in the FICare group (70%, 279 of 396) than in the standard care group (63%, 394 of 624)
	Shi-wen [17], China	2018	Pre-post intervention study	FICare group had significantly increased breastfeeding rates (83% versus 71%) and breastfeeding time (31 days versus 19 days)
	O'Brien [5], Canada	2013	Pilot RCT	There was a significant increase in the incidence of (any)

				breastfeeding at discharge (82% versus 46%)
	Levine, [4] Estonia	1994	Prospective observational study	Breastfeeding rates were higher in the FICare group (80% versus 75%)
	Mohan [14], India	1986	Prospective observational study of two groups	Breastfeeding at discharge increased from 9% to 64%
	Karan [15], India	1983	Pre-post intervention study	Breastfeeding at discharge increased from 10% to 38%
Improved weight gain	O'Brien [6], Canada Australia, and New Zealand	2018	Multicentre prospective cluster RCT	At day 21, weight gain was greater in the FICare group than in the standard care group (mean change in Z scores -0·071 [SD 0·42] versus -0·155 [0·42])
	Shi-wen [17], China	2018	Pre-post intervention study	Significantly higher daily weight gain in the FICare group compared to the standard care group (29 grams/day versus 23 grams/day)
	O'Brien [5], Canada	2013	Pilot RCT	Higher rate of change in weight gain
	Levine [4], Estonia	1994	Prospective observational study	Greater weight gain during the first 30 days of life in the FICare group
	Karan [15], India	1983	Pre-post intervention study	Increase weight gain from mean of 17 to 26.5 grams/day
Parental mental health	O'Brien [6], Canada Australia, and New Zealand	2018	Multicentre prospective cluster RCT	At day 21, parents in the FICare group had significantly lower mean stress scores than parents in the standard care group (2·3 [SD 0·8] versus 2·5 [0·8]), and lower mean anxiety scores (70·8 [20·1] versus 74·2 [19·9])
	O'Brien [5], Canada	2013	Pilot RCT	Parental stress score for FICare mothers was 3.06 ± 0.12 at enrolment, which decreased significantly to 2.30 ± 0.13 at discharge
Discharge / length of stay	Benzies [18], Canada	2020	Multicentre prospective cluster RCT	Length of stay was 2.55 days (95% CI – 4.44 to – 0.66) shorter for the FICare group
	Mingyan [16], China	2020	Multicentre prospective cluster RCT	Length of stay was shorter for the FICare group (28.26 versus 35.04 days; mean ratio 0.81, 95% CI 0.72-0.91)
	Banerjee [7], UK	2019	Pre-post intervention	Reduced CGA at discharge; median 36^{+0} versus 37^{+1} with shorter

			study	length of stay; median 41 versus 55 days
	Butta [19], Pakistan	2004	Pre-post intervention study	Length of hospital stay fell from 34 (SD 18) days to 16 (SD 14) days
	Karan [15], India	1983	Pre-post intervention study	Mean hospital stay was reduced from 40 to 22 days
Readmission	Mingyan [16], China	2019	Multicentre prospective cluster RCT	Rehospitalisation rates were lower in the FICare group (3.65% versus 7.48%)
	Bastani [20], Iran	2015	Pilot RCT	Reduced neonatal readmission rate in FICare group (4.3% versus 18.2%)
Behavioural outcomes	Church [21], Canada	2020	Multicentre cluster RCT, Canadian cohort	FICare in the NICU has a sustained effect on child behaviour, improving self-regulation at 18–21 months corrected age

Appendix 2. Links to useful resources relating to FICare

FICare-related resources

- FICare resources, Mount Sinai Hospital, Toronto
- Imperial College NHS Healthcare Trust Integrated Family Delivered Care (IFDC) Project
- Canadian Preterm Babies Foundation;
- European Foundation for the Care of Newborn Infants (EFCNI)

Parent support and empowerment

- Miracle Babies Foundation
- Support 4 NICU Parents
- NICU foundation YouTube page which hosts animated guides to life on the neonatal unit designed to familiarise parents with the environment and help alleviate some of their worries
- Best Beginning and Small Wonders short films
- Leake, N. (2019) Surviving Prematurity (Book)

Accreditation for neonatal units delivering FICare

- Bliss Baby Charter
- UNICEF BFI Neonatal Standards

Developmental care training and resources

- NIDCAP
- FINE Training & Toolkits
- Early Babies website

Generic quality improvement resources

- BAPM QI Made Easy
- NHS Scotland Quality Improvement Hub
- Institute for Healthcare Improvement
- Maternal and Neonatal Safety Improvement Programme (MatNeoSIP)

COVID-19 specific resources

- BAPM COVID-19 specific resources

Appendix 3. Real Examples of FICare

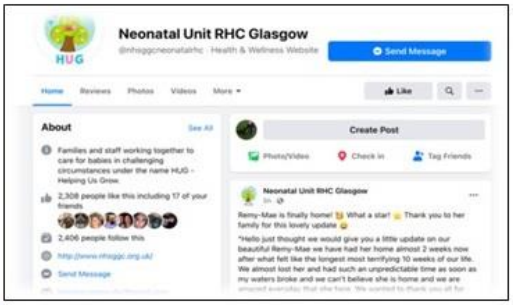
Partnership: My Journey booklet, Leeds Centre for Newborn Care.

"My Journey" is a parent-held booklet that records each families journey, learning to care for their baby and supporting them with information about the neonatal journey. As babies move through their journey it goes with them, as their "passport" in a new unit.

Empowerment: Family Awareness Sessions, Royal Hospital for Children, Glasgow

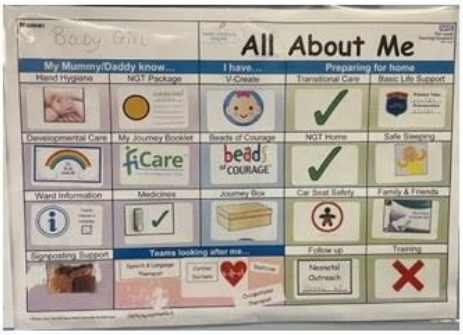
Our monthly schedule of family awareness sessions are opportunities for parents and relatives to learn new skills, meet and support each other

Empowerment: Social Media, Royal Hospital for Children, Glasgow



Our social media pages are an important way for us to communicate with families, past and present, and a key part of our FICare approach. Over 70% of families access them. We post updates of activities and training sessions for families, and our Unit meetings. Families often post updates after discharge and share their experiences, creating positive connections with other families and staff

Empowerment: All About Me boards, Leeds Centre for Newborn Care



"All About Me" bedhead boards illustrate and celebrate each families involvement with care and learning. Each new magnet is another goal achieved in the families journey.

Environment: Supersibs Play Programme, Leeds Centre for Newborn Care.

Sibling playroom staffed by trained & vetted volunteers to enable parents time with their newborn whilst their other children are cared for.

Culture: Implementing delivery room cuddles, Imperial College Healthcare NHS Trust, London

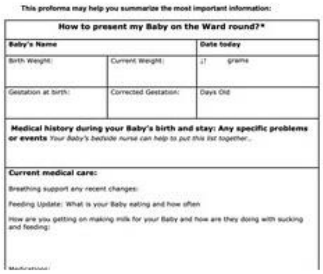
Delivery room cuddles, if safety criteria are met, all preterm babies can have a cuddle with their parents to facilitate bonding in our units. Feedback from parents is extremely positive, many have said that these minutes were their only 'normal' and positive memories of the delivery.

Partnership: Parent support mobile application, Imperial College Healthcare NHS Trust, London

Integrated Family Delivered Neonatal Care
Expert in your baby's care

The Integrated Family Delivered Care (IFDC) App is an innovative smartphone mobile application that helps parents through their NICU journey in the ethos of FICare.
It offers an up to date, comprehensive educational material, developmental timeline and diary functions.
Scan QR code or search for IFDC to download the app.

Empowerment: Parent-led multidisciplinary ward round, Imperial College Healthcare NHS Trust, London



This proforma may help you summarize the most important information:

How to present my Baby on the Ward round?*		
Baby's Name		Date today
Birth Weight:	Current Weight:	↓? grams
Gestation at birth:	Corrected Gestation:	Days Old
Medical history during your Baby's birth and stay: Any specific problems or events *Your Baby's bedside nurse can help to put this list together...*		
Current medical care: Breathing support any recent changes: Feeding Update: What is your Baby eating and how often How are you getting on making milk for your Baby and how are they doing with sucking and feeding:		

Parents are encouraged to participate at any ward round and our weekly MDT ward round is always parent led. The proforma is for parents to fill, supported by the bedside nurse to aid ward round presentation. Parent led ward rounds are an easy tool to shape the FICare culture in the unit.

Partnership: Neonatal Video Diaries, Royal Hospital for Children, Glasgow

Parents told us they would like to receive videos of their baby when they couldn't be with them. We helped to develop and implement a secure video diary service (www.vcreate.tv).
Staff can get very creative to personalise videos for babies. Parents tell us the service makes them feel reassured, more involved, and more connected to the team.

Partnership: Helping Us Grow, HUG, Royal Hospital for Children, Glasgow

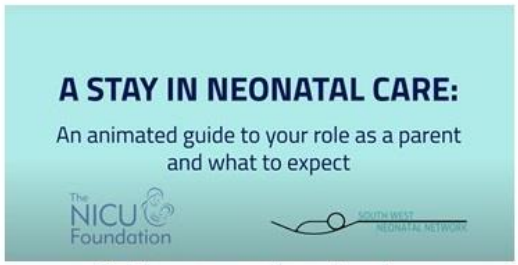
Helping us Grow, HUG, is our collaboration of families and staff in the Neonatal Unit. We meet together at our regular HUG meetings, to hear families' and staff experiences and to develop and implement FICare ideas together.

Everyone is welcome!

Environment: Fingerprint Door Entry, Royal Hospital for Children, Glasgow

We installed a biometric fingerprint entry system so that parents don't have to wait outside or ask permission to see their own baby. It lets parents know they are trusted members of the team, and that this is our shared environment.
The Unit is quieter too, and staff are no longer distracted by answering the doorbell.

Empowerment: "A stay in neonatal care" an animated film, South West Neonatal ODN.



Click here to see the animation

An animated guide to life on the neonatal unit for parents from The NICU Foundation and SWODN. It aims to help alleviate some of the worries that parents may have and includes information about the equipment, noises, facilities and support available to them. The film also describes the latest advice about the benefits of interacting with and holding a premature or poorly baby.

Partnership: Neonatal Parent and Family Conference, South West Neonatal ODN

"Very informative day - great selection of talks. Good location too - central, lots of parking and nice food. Awesome to have a crèche with such friendly staff - my son loved the ball pit! So glad I attended - thought I would be there for a few hours, but stayed all day!" Mum, Bristol

"For the first time since having my prem baby I felt at home (post hospital). I spent the day on the verge of tears as everything was relatable to me and made me realise I had felt alone in this but now I don't! Mum, Exeter

Region wide conferences designed for and with families that have had a neonatal journey within the last five years. Talks on child development, education, promoting motor development, weaning, parent wellbeing etc. Network Parent representatives there to provide advocacy, guidance and support to parents.

Culture : FICare Training, Evelina London Children's Hospital

FICare training for staff, co-designed with parents and delivered by staff champions whilst on shifts. Frequent, short and easily accessible learning bursts ensure that education reaches all staff. It is an effective and simple way to spread the FICare message.

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