

Family Integrated Care A Framework for Practice

November 2021

Contents

Contents	2
Members of the Working Group	3
Introduction	4
What is FICare?	5
FICare culture	6
What is the rationale behind and evidence for FICare?	7
What does FICare mean for families?	8
What does FICare mean for staff?	9
How do neonatal units implement FICare?	10
COVID-19 and FICare	11
The Model of FICare	11
Key components of FICare on neonatal units	13
Implementing the FICare framework at neonatal network level	16
Key components of FICare within neonatal networks	16
Appendix 1. Summary of evidence in support of FICare	19
Appendix 2. Links to useful resources relating to FICare	25
Appendix 3. Real Examples of FICare	27

Members of the Working Group

Chair - Dr Judith Simpson, Consultant Neonatologist, Royal Hospital for Children, Glasgow

Debbie Bezalel, Services Director, Bliss

Dr Nikki Crowley, ST7, Evelina London Children's Hospital

Dr Aniko Deierl, Consultant Neonatologist, Imperial College Healthcare NHS Trust

Nadia Leake, Parent Representative

Rebecca Lemin, South West Head of Maternity and Perinatal Networks and Programmes (NHSE & NHSI)

Chelsie Letts, Baby Charter Programme Lead, Bliss

Dr Maha Mansour, Consultant Neonatologist, Singleton Hospital

Dr Liz McKechnie, Consultant Neonatologist, Leeds Centre for Newborn Care

Dr Neil Patel, Consultant Neonatologist, Royal Hospital for Children, Glasgow

Grazia Sinar, Clinical Matron for Post-natal ward, Transitional care and NNU BNHH, Hampshire Hospitals NHS Trust

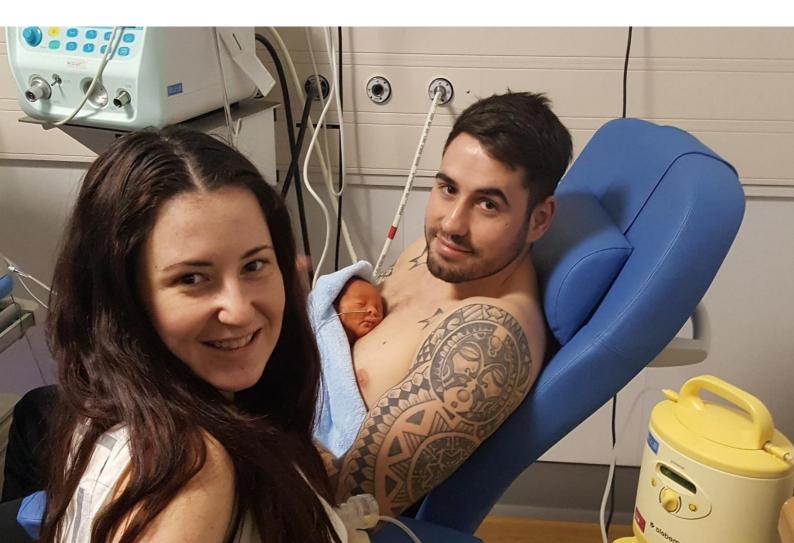
Introduction

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

This framework describes a 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 veteran neonatal unit parent below:

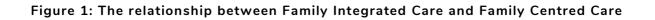
"Help us to help them be the best child they can be, by enabling us to be the best parents we can be from day one".

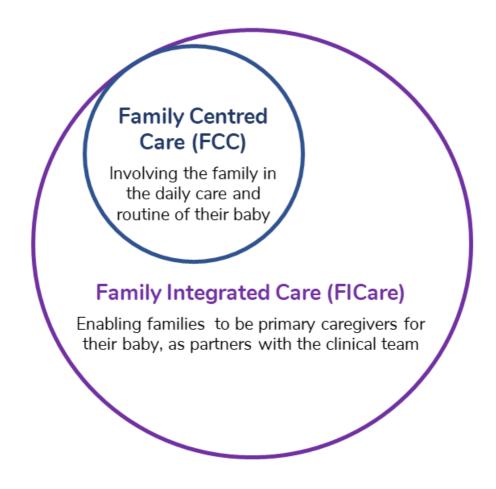


What is FICare?

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 families 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 they can be a family as soon as possible; creating space for necessary medical care whilst facilitating the nurturing bond and love that only they can provide for their baby.

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 family involvement in care to supporting them as equal partners in the care team and primary caregivers (Figure 1).





FICare culture

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 families, as families. This does not come from ticking boxes and investing in practical resources – it evolves from the FICare innovators supporting, educating, and empowering their team, and leading by example.



What is the rationale behind and evidence for FICare?

The FICare philosophy is inspired by innovative practice in resource-limited settings where "care-by-family" is a necessity associated with improved outcomes [4]. These pioneering models of care recognise that the well-being of mothers and babies are inter-dependent; and on a practical level ensure that families can be with and care for their baby 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 family" 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 babies and their families [6, 7]. Importantly involving families in care and decision making has been shown to promote bonding [8] and to enhance confidence at discharge [9, 10] which have benefits for the long-term outcomes of babies and their 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 families 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 quotes and word cloud below, describes how FICare has benefitted and challenged the clinical team. This word cloud was informed by a staff survey at Imperial College NHS Healthcare Trust following the implementation of their FICare bundle in 2017-18.



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 may look slightly different in different units. Teams need to be flexible and adaptive to the resources available to them and the differing needs of individual families, but must also be mindful that consistency of approach across neonatal units and networks is important if families are to receive streamlined care.

A new role for staff

One of the greatest challenges of FICare delivery is for staff to embrace new roles; supporting families, listening to them and hearing 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 families as equal partners in the multidisciplinary team and engaging them in the decision-making process is a journey which can start with small steps 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 them to deliver care as the primary caregivers to their babies.

Funding

FICare at its fundamental base can be implemented at relatively lost cost however it must be recognised that additional funding is required for successful and sustained implementation. This is especially relevant for dedicated staffing, education and environmental modifications.

Utilising existing resources

Appendix 2 outlines some existing resources, including an example of a FICare selfassessment tool, which neonatal units and networks can use to assess their progress in the implementation of FICare against the five principles discussed below.

COVID-19 and FICare

The COVID-19 pandemic has severely impacted the delivery of FICare [12]. Infection control policies, in particular the concept of "parents as visitors", prevented families from being present and involved in their babies' care, and restricted the support available to them from neonatal staff, extended family members and community services. Health and wellbeing of babies, families and neonatal staff have been compromised. 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 Model of FICare

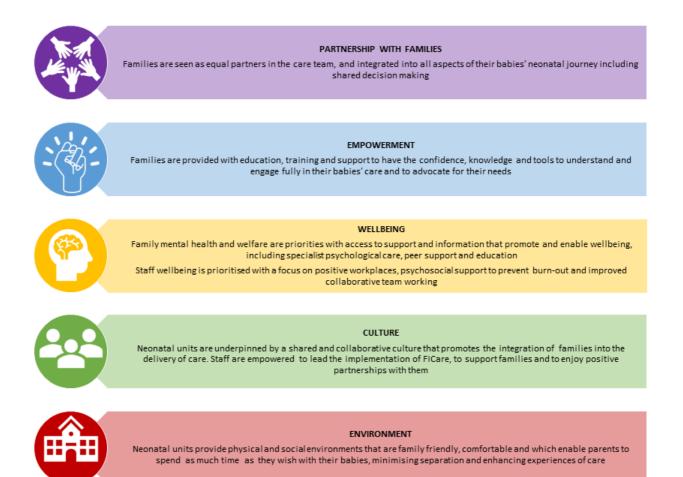
This model of FICare (Figure 2) includes five key principles (Figure 3). Embedding each of these principles into the development and delivery of care on neonatal units and within networks will enable the growth of a FICare philosophy.

These principles are based on the "pillars" of FICare first developed by O'Brien and colleagues in 2013 at the Mount Sinai Hospital in Toronto [5], which inspired early FICare programmes in the UK and internationally. FICare 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 FICare models implemented in the future.



Figure 2. The model of FICare

Figure 3. The five key principles of FICare



Key components of FICare on neonatal units

Each of the five FICare principles comprise 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 FICare principles



Partnership with Families on Neonatal Units

- Positive, mutually respectful partnerships are established between staff and families, with families supported to become involved in their babies' care as primary caregivers
- From admission (or before in high-risk pregnancies anticipated to result in neonatal admission) families are supported and encouraged to be comfortable providing care for their babies
- Families are supported to be actively involved in ward rounds, daily care planning and decision-making
- Families have opportunities to give feedback about their babies' care while on the unit and after discharge
- Families' experiences and feedback are actively sought, to inform and improve the quality of services
- Technology and innovations are used to support family participation in care
- Local FICare steering groups comprising families, parent advisory groups and members of the multidisciplinary team are established to drive improvement



Empowerment on Neonatal Units

- Families are orientated to the neonatal unit environment before (if admission anticipated) or on admission
- Families have access to information which outlines their role as caregivers and the philosophy of an integrated approach to delivering neonatal care
- Ongoing orientation to support services available to families during their stay, including engagement with local charities and third sector organisations
- Provision of a structured education program for families
- Ongoing individual skills teaching and support for families at the cot side
- Family classes and activities offered at convenient times including out of hours, evenings and weekends
- Opportunities actively created for peer-to-peer learning



Wellbeing on Neonatal Units

- Families and staff have access to specialist psychological and mental health support on the unit and after discharge
- Regular unit and community-based opportunities for peer-to-peer support / family group activities
- Consideration of the use of family liaison officers
- Pro-active use of appropriate translation services and written literature in different languages to mitigate the impact of language barriers
- Inclusive and equitable access for all families
- Clear processes for ensuring consistent family access when transferring between units
- Wellbeing activities are offered to all families (e.g. yoga, crafting, meditation) and staff
- Engagement with local charities, third sector organisations and community groups providing wellbeing support for families

Culture on Neonatal Units

- Education and training activities for all neonatal team members on the philosophy and benefits of FICare and the expectations of their practice to support families
- FICare education and training included in staff orientation and annual skills updates
- Staff training in communication, coaching and mentoring skills
- 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 families in all aspects of the development and delivery of neonatal care locally



Environment on Neonatal Units

- A welcoming and shared neonatal unit environment including a dedicated family rest room, kitchen facilities for heating and storing food and personal storage space
- 24-hour open access for families to be with their babies, including during ward rounds and nursing handovers
- A comfortable cot-side environment with access to reclining chairs, breast pumps and screens for privacy
- A dedicated room for mothers to express breast milk in comfort and if preferred privacy
- Pro-active signposting of financial support for families including for travel costs, food and parking
- Pathways to ensure streamlined and consistent 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 family 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. The adoption of a network vision for FICare will have a number of direct benefits including to:

- Provide a clear structure and direction of travel for the adoption and implementation of FICare across the network
- Motivate and enthuse units about FICare
- Improve consistency and continuity of care across network 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 FICare



Partnership with Families in the Neonatal Network

- Network commitment and leadership to support and value FICare
- Family and staff involvement in all aspects of the development and delivery of FICare at network level
- Network approach to implementing the FICare Framework



Empowerment in the Neonatal Network

- Shared and consistent network family education resources
- Network materials that promote the consistent delivery of FICare across all units e.g., animations, paperwork such as parental passports / competency packages and information leaflets
- Access to neonatal unit virtual tours and a single network information portal e.g., website, social media
- Information for families on neonatal care and network pathways, including the concept of optimal place of birth / delivery of specialist care and timely repatriation
- Support for local, regional and national campaigns, and engagement with charities to ensure representation of the neonatal voice at a national level



Wellbeing in the Neonatal Network

- Collect and review families' feedback of their experiences as network service users, use of this information to inform developments
- Work with charities / third sector organisations supporting neonatal care to ensure equitable access to peer support / parent groups
- Ensure an inclusive network approach to the implementation of the FICare Framework for all families
- Utilisation of Care Coordinators (England only) to promote a streamlined approach to FICare by sharing learning regionally and nationally
- Development of network pathways to access specialist psychology support for families and training to staff on the psychological needs of families

Culture in the Neonatal Network

- Network staff training resources, information and guidelines
- Support for innovations / QI projects that support FICare
- Provide support / educational resources to ensure that FICare is included in induction, QIS and training programmes for all staff groups involved in neonatal care
- Fund programmes which enhance skills and promote continuity and consistency across the network



Environment on Neonatal Units

- Development a network strategy for the equitable provision of parental facilities including accommodation
- Advocate for transitional care in all units to minimise separation of mother and baby
- Develop a network strategy which identifies units requiring re-design and expansion, and provide support to obtain capital funding
- Clear and agreed paediatric transition pathways across the network
- Annual network peer review against existing FICare Quality Standards e.g., parental presence on ward rounds

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 [13], India	1986	Prospective observational study of two groups	Reduced mortality (12.7% versus 33.1%)
	Karan [14], India	1983	Pre-post intervention study	Reduced mortality (5.5% versus 5.0%)
Infection	Mingyan [15], 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 [13], India	1986	Prospective observational study of two groups	Reduced mortality from neonatal sepsis (12% versus 34%)

Breastfeeding at discharge	Mingyan [15], 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 [16], 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 [13], India	1986	Prospective observational study of two groups	Breastfeeding at discharge increased from 9% to 64%

	Karan [14], India	1983	Pre-post intervention study	Breastfeeding at discharge increased from 10% to 38%
, weight gain C	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 [16], 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 [14], 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 /	Benzies [17],	2020	Multicentre	Length of stay was 2.55 days (95% CI – 4.44 to – 0.66)
length of stay	Canada		prospective cluster RCT	shorter for the FICare group
	Mingyan [15], 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 study	Reduced CGA at discharge; median 36 ⁺⁰ versus 37 ⁺¹ with shorter length of stay; median 41 versus 55 days
	Butta [18], Pakistan	2004	Pre-post intervention study	Length of hospital stay fell from 34 (SD 18) days to 16 (SD 14) days
	Karan [14], India	1983	Pre-post intervention study	Mean hospital stay was reduced from 40 to 22 days
Readmission	Mingyan [15], China	2019	Multicentre prospective cluster RCT	Rehospitalisation rates were lower in the FICare group (3.65% versus 7.48%)
	Bastani [19], Iran	2015	Pilot RCT	Reduced neonatal readmission rate in FICare group (4.3% versus 18.2%)
Behavioural outcomes	Church [20], 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

References

- 1. Bliss Baby Charter. Available online at: <u>https://www.bliss.org.uk/health-professionals/bliss-baby-charter</u>
- Roué JM, Kuhn P, Lopez Maestro M, et al. Eight principles for patient-centred and family-centred care for newborns in the neonatal intensive care unit. Arch Dis Child Fetal Neonatal Ed. 2017 Jul;102(4):F364-F368. doi:10.1136/archdischild-2016-312180. Epub 2017 Apr 18.
- 3. Flacking R, Lehtonen L, Thomson G, Axelin A, Ahlqvist S, Moran VH, et al. Closeness and separation in neonatal intensive care. Acta Paediatr. 2012;101(10):1032-7.
- 4. Levin A. The Mother-Infant unit at Tallinn Children's Hospital, Estonia: a truly babyfriendly unit. Birth. 1994;21(1):39-44, discussion 5-6.
- 5. O'Brien K, Bracht M, Macdonell K, McBride T, Robson K, O'Leary L, et al. A pilot cohort analytic study of Family Integrated Care in a Canadian neonatal intensive care unit. BMC Pregnancy Childbirth. 2013;13 Suppl 1:S12.
- O'Brien K, Robson K, Bracht M, et al. Effectiveness of Family Integrated Care in neonatal intensive care units on infant and parent outcomes: a multicentre, multinational, cluster-randomised controlled trial. Lancet Child Adolesc Health 2018;2:245–54.
- Banerjee J, Aloysius A, Mitchell K, et all. Improving infant outcomes through implementation of a family integrated care bundle including a parent supporting mobile application. Archives of Disease in Childhood - Fetal and Neonatal Edition 2020;105:172-177.
- 8. Wigert H, Berg M, Hellstrom AL. Parental presence when their child is in neonatal intensive care. Scand J Caring Sci. 2010;24(1):139-46.
- 9. Dellenmark-Blom M, Wigert H. Parents' experiences with neonatal home care following initial care in the neonatal intensive care unit: a phenomenological hermeneutical interview study. J Adv Nurs. 2014;70(3):575-86.
- 10. Franck LS, Axelin A. Differences in parents', nurses' and physicians' views of NICU parent support. Acta Paediatr. 2013;102(6):590-6.
- 11. Kirolos S, Sutcliffe L, Giatsi Clausen M, et al. Asynchronous video messaging promotes family involvement and mitigates separation in neonatal care. Arch Dis Child Fetal Neonatal Ed. 2021 Mar;106(2):172-177. doi: 10.1136/archdischild-2020-319353. Epub 2020 Sep 14.

- van Veenendaal NR, Deierl A, Bacchini F, O'Brien K, Franck LS, International Steering Committee for Family Integrated Care. Acta Paediatr. Epub 2021 March 26. doi:10.1111/apa.15853.
- 13. Mohan VM, Karan S. Maternal involvement in the care of high risk infants in a sick newborn nursery--a prospective study. Indian Pediatr. 1986;23(2):121-5.
- 14. Karan S, Rao SS. Benefits of early maternal participation in care of low-birth-weight infants leading to early discharge. J Trop Pediatr. 1983;29(2):115-8.
- 15. Mingyan Hei, Xiangyu Gao, Ying Li et al. Family Integrated Care for Preterm Infants in China: A Cluster Randomized Controlled Trial. J Pediatr2021 Jan;228:36-43.e2. doi: 10.1016/j.jpeds.2020.09.006.
- 16. Shi-wen He, Yue-e Xiong, Li-hui Zhu et al. Impact of family integrated care on infants' clinical outcomes in two children's hospitals in China: a pre-post intervention study. Ital J Pediatr. 2018; 44: 65. Published online 2018 Jun 5. doi: 10.1186/s13052-018-0506-9
- 17. Benzies KM, Aziz K, Shah V, et al. Effectiveness of Alberta Family Integrated Care on infant length of stay in level II neonatal intensive care units: a cluster randomized controlled trial. BMC Pediatr. 2020;20(1):535. Published 2020 Nov 28. doi:10.1186/s12887-020-02438-6
- Bhutta ZA, Khan I, Salat S, Raza F, Ara H. Reducing length of stay in hospital for very low birthweight infants by involving mothers in a stepdown unit: an experience from Karachi (Pakistan). BMJ. 2004;329(7475):1151-5.
- Bastani F, Abadi TA, Haghani H. Effect of Family-centered Care on Improving Parental Satisfaction and Reducing Readmission among Premature Infants: A Randomized Controlled Trial. J Clin Diagn Res. 2015;9(1):SC04-8.
- 20. Church PT, Grunau RE, Mirea L, et al. Family Integrated Care (FICare): Positive impact on behavioural outcomes at 18 months. Early Hum Dev. 2020 Dec;151:105196. Epub 2020 Sep 19. doi: 10.1016/j.earlhumdev.2020.105196.

Appendix 2. Links to useful resources relating to FICare

FICare-related resources

- FICare resources, Mount Sinai Hospital, Toronto; <u>http://familyintegratedcare.com/</u>
- Imperial College NHS Healthcare Trust Integrated Family Delivered Care (IFDC) Project; <u>https://ifdc-familyintegratedcare.com</u>
- Neonatal unit FICare self-assessment tool available via https://ifdc-familyintegratedcare.com
- Canadian Preterm Babies Foundation; <u>https://www.cpbf-fbpc.org/</u>
- European Foundation for the Care of Newborn Infants (EFCNI); <u>https://www.efcni.org/health-topics/in-hospital/developmental-care/</u>

Parent support and empowerment

- Brazelton Centre UK; <u>https://www.brazelton.co.uk/</u>
- Miracle Babies Foundation; https://<u>www.miraclebabies.org.au</u>/
- Support 4 NICU Parents; <u>www.support4nicuparents.com</u>
- 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; <u>https://youtube.com/channel/UCN_7YreEPxItjwME5vFa5UQ</u>
- Best Beginning and Small Wonders short films; https://www.bestbeginnings.org.uk/smallwonders/
- Leake, N. (2019) Surviving Prematurity

Wider resources to support neonatal care

- Bliss Baby Charter; https://www.bliss.org.uk/health-professionals/bliss-baby-charter
- UNICEF BFI Neonatal Standards; <u>https://www.unicef.org.uk/babyfriendly/baby-</u> <u>friendly-resources/implementing-standards-resources/neonatal-guide-to-the-</u> <u>standards/</u>

Developmental care training and resources

- Sensory Babies; <u>https://www.sensorybeginnings.com/</u>
- NIDCAP; <u>https://nidcap.org/en/</u>
- FINE Training & Toolkits; <u>https://finetraininguk.com/</u>
- https://www.earlybabies.com/

Generic quality improvement resources

- BAPM QI Made Easy <u>https://www.bapm.org/pages/58-qi-made-easy</u>
- NHS Scotland Quality Improvement Hub: <u>https://ihub.scot/</u>

- Institute for Healthcare Improvement: http://www.ihi.org/resources/Pages/default.aspx
- Maternal and Neonatal Safety Improvement Programme (MatNeoSIP): <u>https://www.england.nhs.uk/mat-transformation/maternal-and-neonatal-safety-</u> <u>collaborative/</u>

COVID-19 specific resources

• BAPM COVID-19 specific resources; <u>https://www.bapm.org/pages/181-family-integrated-care-covid-19-resources</u>

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.

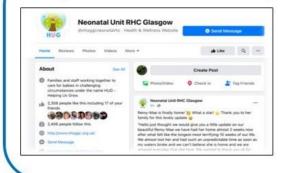
Empowerment: Family Awareness Sessions, Royal Hospital for Children, Glasgow



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

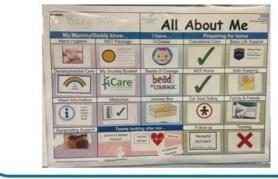


Empowerment: Social Media, Royal Hospital for Children, Glasgow



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



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



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 (<u>www.vcreate.tv</u>).

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.

A STAY IN NEONATAL CARE:



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 Awazome 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!" Murn, 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.