

Liam Blundell¹, Milly Munn¹, Anna Lukens¹, Kerry Engelbrecht¹, Sarah Neilson¹,
Ebony Blewer¹, Elaine Wood¹, Maya Asir¹, Dr. Sonal Datir¹

¹ Neonatal Department, Evelina Children's Hospital (ELCH), Guy's and St Thomas' NHS Foundation Trust, London.

Background

Skin-to-skin contact (SSC) or "Kangaroo Care":
Parents holding their baby against their skin.

Snapshot audit: 30.5% of infants get SSC/day, ~38 mins/infant/day. This identified a need to improve SSC practices on the neonatal unit.

Snapshot audit: 30.5% of infants get SSC/day, ~38 mins/infant/day. This identified a need to improve SSC practices on the neonatal unit.



Aims

To increase rates of SSC (% babies & total time of SSC) by 50%

Methodology

Audit of SSC

Education & Awareness Week

Kangaroo Care Day 15th May 2024

- Bedside nurses supporting SSC & documenting
- AHP's/FiCare Nurses helping with:
 - Transfers out for SSC
 - Education on benefits



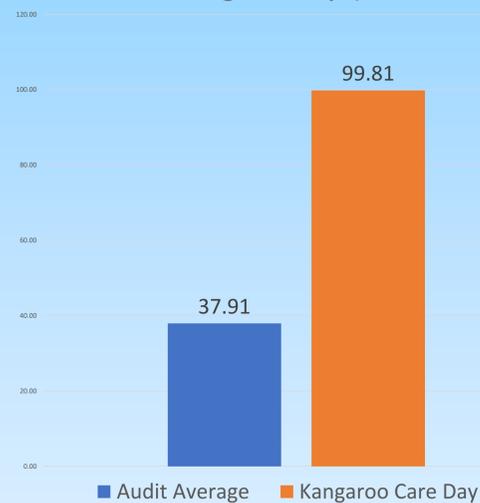
Benefits of SSC:

↑ CVS/Resp/Temp stability
Breastfeeding/Milk production
Neurodevelopmental outcomes
Sleep

↓ Pain
Cortisol

Results & Table

SSC Average/Baby (Minutes)



% Babies Receiving SSC



Conclusion

SSC practices can be improved with education and awareness on the importance of SSC for infants outcomes alongside physical support to facilitate it. To continue improvement, ongoing PDSA cycles should identify and alter barriers to ensure SSC is integrated into daily care.

References

1. Jeffries, A. L., 2012. Kangaroo care for the preterm infant and family. Paediatric Child Health, 17(3), pp. 141-143.
2. Wood, E., 2022. Skin to skin (kangaroo care) for the preterm baby or sick neonate. [Online] Available at: <https://app.clinibee.com/articles/0c1e2449-cc45-4c44-9a79-5f91332d295d> [Accessed 11 June 2024].

Implementing a Paid Veteran Parent Support Role in Mount Sinai Hospital's Neonatal Intensive Care Unit



Abarnaa Vivekanandan RN, BSCN, MN,¹ Professor Karol O'Brien, MBBChBAO, FRCPC, MSc^{1,2}
 Mount Sinai Hospital, Toronto, Ontario, Canada¹; University of Toronto, Toronto, Ontario, Canada²

Background

Aims of Paid Veteran Parent Role

Methods

- Mount Sinai's Neonatal Intensive Care Unit (NICU) has implemented the pillars of Family Integrated Care (FICare) for 12 years
- Maintaining the quality and quantity of parental engagement in infant care has been more difficult since the COVID-19 pandemic
- We postulated that re-introduction of a paid Veteran Parent role might help us improve FICare in our unit
- The proposed paid veteran parent was to be a parent of an infant born before 32 weeks' gestation
- The objective of this role is to bridge the gap between NICU staff and parents, ensuring active parental involvement in the healthcare team

- Elevate parental voice by enhancing the role of parents in NICU administration and decision-making
- Support NICU families and staff by utilizing lived experience to assist families and staff to improve FICare practice within the NICU
- Educating and supporting through providing informal and structured education to families and staff

Pre-Implementation

- In 2024, Mount Sinai's NICU received funding from the Lang Family Foundation to support a paid veteran parent support role for 12 months
- NICU staff were surveyed on their views about the role and its integration
- Neighboring level III NICU who have had long standing paid parents were consulted, to refine the role's job description and mandate

Impact and Possible Results

This ongoing implementation hopes to:

- Increase parental engagement in infant care at the bedside
- Enhance family support in the NICU
- Improve staff knowledge and perspectives of parent experience
- Provide direct parent input for NICU administration and decision-making processes
- Provide evidence to get hospital funding to continue to support the role

Hiring Process

- Job posting for paid veteran parent was advertised on the MSH website and informed NICU parent advisory committee members
- 14 applications received, 6 candidates were interviewed
- One successful candidate, Beth McBarnett, hired September 2024

Evaluation Plan

- Post-implementation feedback collection using a survey for families, staff, and direct feedback from the paid veteran parent
- Evaluations for impact assessment will guide future refinements of the role and be used to develop a business plan for its sustainability

Mount Sinai Hospital: (abarnaa.vivekanandan@sinaihealth.ca)

We Anticipate That the Paid Veteran Parent Will

- Be effectively integrated into the NICU Leadership team
- Provide valuable emotional and practical support to NICU families
- Foster better collaboration and understanding between NICU staff and parents
 - Promote a culture of continuous learning and improvements

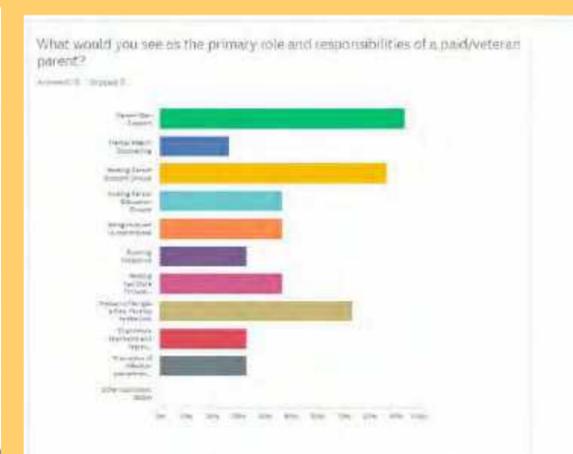


Figure 1: Biography of successful paid veteran parent Beth McBarnett

Figure 2: Example of survey sent to NICU staff about paid veteran parent role pre-implementation

From Fika to FiCare: A parent-led workshop exploring ways to embed FiCare in our local region

Ailie Hodgson, Rachel Collum & Claire Campbell

Background

This project was informed by an NNA (Neonatal Nurses Association) travel scholarship to Sweden to understand the 'gold standard' implementation of FiCare practice. We identified resource-independent recommendations to inform practice in our Northern Neonatal Network (NNN). We delivered the recommendations at an innovative parent-led workshop for neonatal staff to further explore how they could be implemented into practice.

Aims

To utilise creative and parent-led methods to understand current perspectives on FiCare of our network staff and families. To disseminate recommendations from Sweden and explore staff barriers and facilitators to translating and embedding these into local FiCare practice.

Pledge cards & pin badges for attendees



Methods

The workshop comprised mixed methods including parent facilitated discussions; creative methods; parent stories; live feedback and pledge cards.

Creative stations showing delegates depicting interpretations of FiCare with play doh and plastic figures



Creative stations showing delegates depicting interpretations of FiCare through collaging



Results

Discussions indicated that progress is being made in FiCare across the NNN, with examples of increased parent involvement in care and addressing parent and staff wellbeing. However, discussions also highlighted that practice is variable with inconsistencies in skin to skin, family resources and education. Common barriers identified were different staff viewpoints and changing ingrained practice habits. Live feedback at the beginning and end of the workshop showed a difference in how parents and staff see their roles with regards to FiCare. Pledge cards and feedback suggested staff have a clear view of how they can improve their practice to influence FiCare in the NNN.

Parent facilitated tabletop discussions



Conclusion

Parent-led discussion, alongside a mix of interactive, creative formats enabled open dialogues about staff and parent roles and their perceptions of FiCare. The traditional power imbalance and clinical environment that can exist in neonatal care was mitigated, creating a safe platform for sharing ideas based on the Swedish model. Hope for improvement was highlighted from one parent who attended the workshop: **"I don't think we should limit ourselves from dreaming that Sweden's vision could be possible."**

Creative depictions of FiCare made by workshop delegates out of modelling clay and plastic figures



References

- Collum, R. et al (2024). Confidence not Competence: Reframing roles to embed FiCare. *Journal of Neonatal Nursing*, 30, 88-91
- Facking, R., Thomson, G., & Axelin, A. (2016). Pathways to emotional closeness in neonatal units – a cross-national qualitative study. *BMC Pregnancy and Childbirth*, 16(1), 170. <https://doi.org/10.1186/s12884-016-0955-3>
- Thernström Blomqvist, Y., Ågren, J., & Karlsson, V. (2022). The Swedish approach to nurturing extremely preterm infants and their families: A nursing perspective. *Seminars in Perinatology*, 46(1), 151542. <https://doi.org/10.1016/j.semperi.2021.151542>

Acknowledgements & Affiliations

We would like to thank Sunderland University, The Neonatal Nursing Association and the Northern Neonatal Network



Every Baby Matters

parent and staff perspectives on early relationship support in a paediatric setting

One of the greatest gifts we can give to others is the gift of attention and presence. In the realm of infant mental health, it is through our relationships that we heal and grow." T. Berry Brazelton

Casey, A.M.^{1,2}, Coey, P.¹, Dunne, J.², Twohig, A.³, McKay, C.⁴, McMahan, C.⁵, & McHughPower, J.⁵

1 Department of Paediatric Psychology, CHI at Crumlin; 2 Department of Neonatology, CHI at Crumlin; 3 Department of Psychiatry, CHI at Temple Street; 4 Department of Speech and Language Therapy, CHI at Temple Street; 5 Department of Psychology, Maynooth University.

Background

During the first 1000 days of a baby's life, the foundations for later development are laid. Babies' brains are shaped by the world around them, through interactions they have with their caregivers. Birth of a child is a developmental touchpoint for parent and infant. Over 1,800 infants admitted to Children's Health Ireland (CHI) every year and growing. Research shows Family Integrated Care and parental collaboration embedded in developmental care in the NICU optimises medical, social, emotional and cognitive outcomes for infants and supports parental wellbeing.

Aims

1. To develop an understanding of what developmental care and infant mental health means to families and staff; 2. To assess the gaps and needs of infant mental health and developmental care; 3. To ascertain the training and educational needs of staff; 4. To assess if working with infants improves staff wellbeing; 5. To see what ways CHI can enhance the awareness and promotion of IMH practices, e.g. enhance bonding, attachment, infant development and parent self-care.

Methodology

A cross sectional questionnaire survey (N=56 staff and N=13 parents). Survey design. Co design with parents using objective measures – Corc Study Confidence Scale Adapted; BIF baby blindspot study; Clonmel Tipperary Staff Survey, Copenhagen IMH Screener (CIMH), Green et al Mental Health Services Adapted Survey. Inter-rater questions reducing down to key themes for this survey, and open ended questions. Mixed Method Analysis: quantitative – general linear analysis – chi square for contingency tables, correlations and regressions. Qualitative analysis: thematic Analysis using an inductive approach (Braun and Clarke, 2006).

Results

Parent feedback:

92% - staff are knowledgeable on how to support infants (90%) confidence in supporting sleeping and feeding
60% - staff show cultural sensitivity
69% - help me bond with my baby
77% - value my input as parents
84% - staff kindness helped them cope

"(Staff) help me to position him on my chest and to lift him from his cot as he has a lot of tubes and wires attached. They encourage me to hold him for as long and as often as I want"

Parent feedback:

"Staff definitely should have more training about interpersonal and communication".

"Staff should be conscious of condescending language and accusatory tones".

Parents observed this could be due to burnout, understaffing, and some who are just not happy in their jobs.

"I would love to be able to spend a few minutes outdoors with my baby every day"

"Supportive caring staff but would be better if more support for parents"
Feedback from Parents at CHI

Staff feedback

Deep commitment to care of parent and infant.
Majority referred to developmental care as milestones / cognitive development
Infant Mental Health universally understood
Benefit of family resources
Report benefit of theoretical frameworks and environment to optimise care
Would like more time with parents and more training

How does working with infants and parents make you (staff) feel?

"It's the best job in the world"

"I feel privileged – being in a position of trust at a sensitive time"

"Nervous at times, you have to be attuned to non verbal cues"

"A little bit anxious as parents can be so understandably frightened themselves"



Future Directions

Together for better care
More family involvement
Outdoor spaces
Continued training for staff
Parent Support Groups and Resources
Family Integrated, E-SIMART Developmental care rounds Rounds

Acknowledgements

Thank you to the parents and staff at Children's Health Ireland and the CHI Infant Mental Health Network Group.

POW!

L.A.D.'S

Looking After Dad's

Brenda Mc Cann & Robert Mulligan



REGIONAL NEONATAL
INTENSIVE CARE UNIT BELFAST



Background:

Fathers of infants admitted to the NICU often experience significant stress, anxiety, feelings of helplessness and long-term effects of PTSD. Despite this knowledge, much of the existing support infrastructure focuses on mothers. The FiCare Model, offers a unique opportunity to address this gap. Current research indicates that involving fathers in the NICU care not only improves infant outcomes but enhances paternal wellbeing.

Aim:

This project aims to explore the impact of tailored support strategies on fathers' experiences during their infants' NICU stay, within the framework of the FiCare Model.

Method:

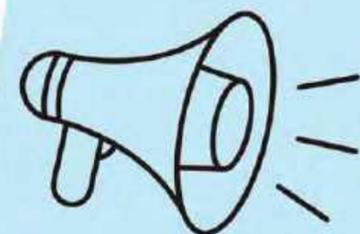
- A mixed method approach was employed
- Questionnaires - distributed to fathers participating in the FiCare project to elicit views of their experience of FiCare in the NICU.
- Formal one on one meet and greet session by the project lead on admission to unit.
- Informal peer support/education sessions addressing needs at individual level, including impact of NICU, transitioning to NICU life, caring for your baby, it's good to talk and men's mental health.
- Informal interviews both with current and veteran fathers through parent advisory group provided qualitative insights to their experiences.



Supporting Fathers in their NICU Journey: Insights from FiCare Implementation QI Project "Heading Home Together" in Tertiary Neonatal Unit

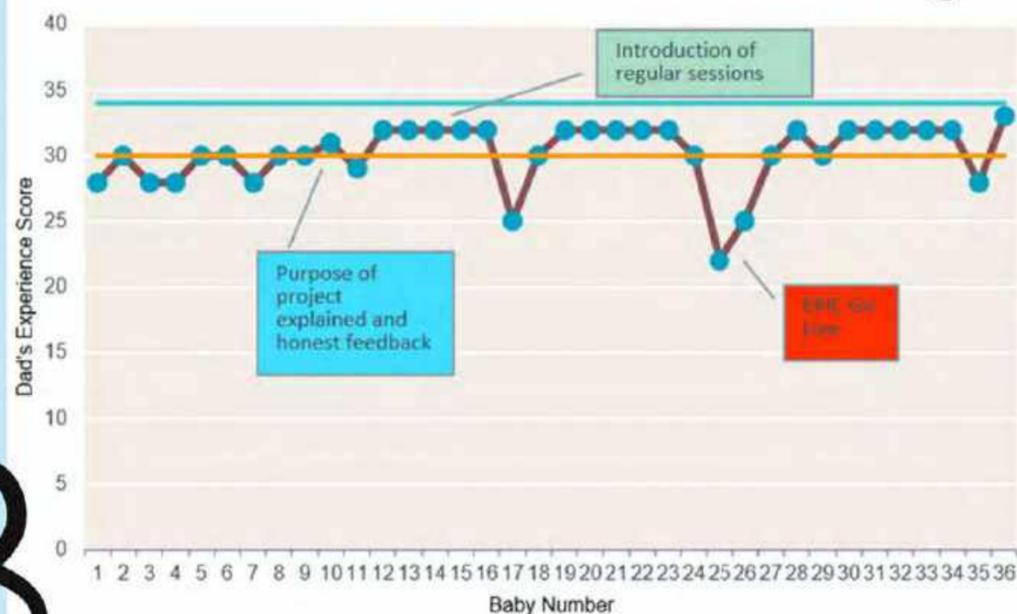
Results:

- 70% of all fathers on the unit have received one on one help and support on their NICU journey.
- Data revealed a reduction in stress and anxiety levels among fathers who participated in the FiCare program.
- Confidence in caregiving skills also showed a marked improvement.
- Highlighted the importance of feeling included and supported.
- Greater emotional stability and a stronger bond with their infants.
- Many fathers emphasized the value of peer support and direct involvement in caregiving as crucial elements of their positive experience.



WOW

LAD's Session Feedback



Helpful and tailored to baby's age. Great to be able to ask questions.

Very informative, great info and leaflets to read at home.

Robert is the most amazing teacher

SUPER DAD

Keep doing them as they are helpful

A family Integrated Care Project

Heading Home Together

B. Rao, C. Black, C. Glover, B. McCann, S. Hollywood, G. Hanna.
Regional Neonatal Unit, Royal Maternity Hospital



Background

Family integrated care is an evidence based model of care that improves outcomes for infants and their families. It is recommended by the British Association of Perinatal Medicine

- The benefits:
- Reduced mortality
 - Reduced infection rates
 - Increased breastmilk feeding
 - Earlier discharge
 - Improved parent wellbeing



Aim Statement

To improve parent experience scores of family integrated care (Ficare) in Regional NICU for high risk infants, born less than 32 weeks by 10% by the end of June 2024

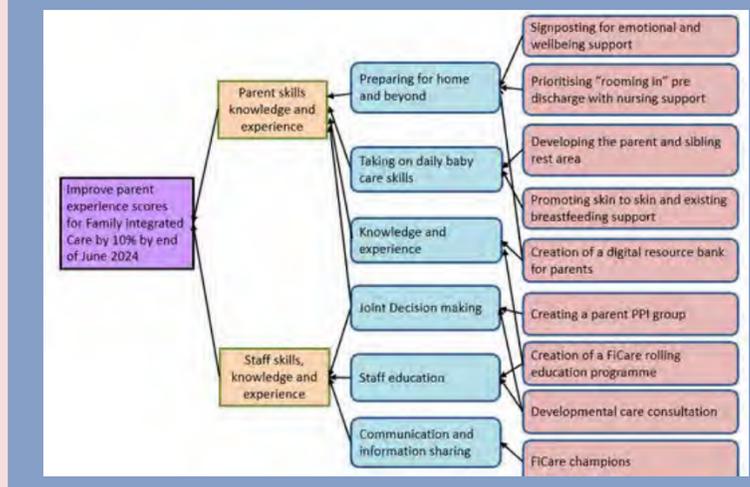
The goal of FICare is to facilitate partnership between parents and NICU staff, to promote parent-infant interactions, and to build parent confidence

- It involves:
- Empowering parents
 - Focusing on parent wellbeing
 - Parent involvement in cares
 - A welcoming and supportive environment
 - Unit culture change



What changes?

Our driver diagram demonstrates the changes we decided to make to achieve this aim



Project Progress in Data

We obtained baseline data demonstrating a median questionnaire score of 104

On reviewing the responses, we recognised parents were being overly generous in their feedback and we explained the purpose of the project more clearly

Subsequent questionnaires reflected more realistic feedback, which shifted the median baseline and therefore the 10% "goal" line

Over time, PDSA cycles had an impact on the parent experience scores

Our Run chart demonstrates that an initial trend upwards in parent experience scores eventually turned into a shift over the goal line, in keeping with a sustained change

Since the EPIC go-Live we have noted a dip below the goal line again and this has given us a new motivation to keep up our changes and refocus from computers at the bedside, back to parents and babies!



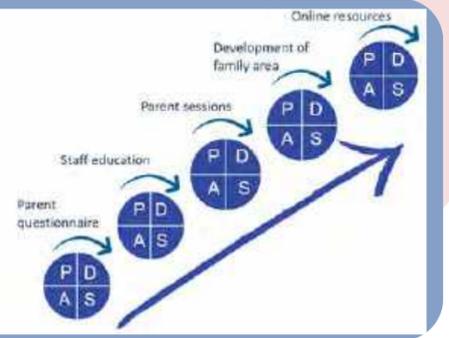
We created a Parent Advisory Group to inform our changes and give a parent perspective on:

- Creating our questionnaire
- Understanding what parents want from the NICU team in supporting FICare
- Developing parent education sessions
- Creating parent friendly resources

PDSA cycles and changes

We created a parent experience questionnaire to capture data. This is a measure of how well we are implementing Ficare and how this impacts parents' experiences taking care of their baby

We implemented PDSA cycles based on change ideas and continually collected data when babies reached 28 days old and at the point of discharge



Parent Voices

"We live 90 miles from the hospital, so we have a lot of travelling. We also have other children at home"

"Thanks for the fantastic parents' program that brings us all together."

"We have been so thankful for the staff and facilities provided!"

"The required milestones to my baby being able to come home have not been clear"

Challenges	Challenges and Learning
<ul style="list-style-type: none"> • Getting questionnaires completed • Time for staff training 	
Learning	
<ul style="list-style-type: none"> • QI Methodology • PPI processes • Developing multiple modes of teaching materials 	
Enjoyment	
<ul style="list-style-type: none"> • Working with past parents • Teamwork across the unit • Seeing the benefit for families 	
Benefit to families	
<ul style="list-style-type: none"> • Confidence in caring for their baby • Holding baby • Siblings meeting earlier 	

What's next?

- Starting a Developmental Care Ward round
- Rolling out the FICare model through the Neonatal Network
- Ongoing liaison with the Parent Advisory Group
- Linking into our Buttercup Discharges Project
- Moving into a New Maternity Hospital with single rooms
- Creating a monthly parent feedback dashboard to create legacy and keep up motivation for change

Improving knowledge and understanding of Family Integrated Care: Delivering staff education across the West Midlands

Curson C,¹ Fox C,¹ Causier J,¹ Raiman C,¹ Evans D^{1,2}

The authors acknowledge the support of the wider West Midlands Perinatal Network team

Attendee Feedback ★★★★★

From a students point of view, it was incredibly valuable to learn about FiCare as this is not taught in addition to pcc and fcc at university

Really interesting and makes you think of the changes you can implement to improve FiCare

The day was very informative, so much to understand and get to know and it was presented very well and all information given was relevant and interesting.

I learnt about not only how to implement FiCare, but why it's so important for parents, families and staff

Very informative day Empowering staff to drive forward positive culture change

How interactive the day was, opportunities to share knowledge and experience, to network and to learn from others and other unit's practice

Network Team Reflection

This was a unique opportunity to deliver universal introductory education to neonatal staff in the West Midlands. We built upon the intelligence gained from staff surveys and a FiCare benchmarking review which highlighted a clear need for education which reinforced the importance of the role of parents and carers in the neonatal unit and addressed misconceptions about FiCare. Targeted attendance was not wholly effective; many attendees already possessed good insight and understanding.

The faculty felt that the programme was not as effective as anticipated. Rather than deliver further FiCare education in silo, the WMPN team started to adapt their strategy to embed the golden threads of Family Integrated, Neuroprotective and Trauma Informed care in current provision.

RELATED LITERATURE

British Association of Perinatal Medicine (2021) Family Integrated Care: A Framework for Practice. Available at: www.bapm.org/resources/ficare-framework-for-practice

NHS England (2019) The NHS Long Term Plan Available at: www.longtermplan.nhs.uk/publication/nhs-long-term-plan

Oude Maatman SM, Bohlin K, Lilliesköld S, Garberg HT, Uitewaal-Poslawky I, Kars. (2020). Factors influencing implementation of Family-centered care in a neonatal intensive care unit. Online at: Family Integrated Care: <https://familyintegratedcare.com/research/>

Background

- A region-wide Training Needs Analysis and staff survey of knowledge and attitudes relating to Family Integrated Care were undertaken by the West Midlands Perinatal Network in 2022.
- Staff feedback highlighted the need for high-quality consistent education.
- Of 14 neonatal units in the region, only 2 included Family Integrated Care in local education.
- Only 3 units had dedicated roles supporting FiCare implementation

Aim of the project

- To raise awareness of the philosophies of Family Integrated and Psychologically Informed Care and the experiences of families.
- To introduce high-quality education for multiprofessional teams across the West Midlands and support local leads to deliver staff education.
- To provide networking opportunities, sharing good practice, and increasing understanding of local barriers to the implementation of FiCare.
- To improve the experience of families.

Methodology

- The WMPN Care Coordinators and Lead Psychologist developed a programme of study days based on staff survey feedback and informal conversations with stakeholders.
- The British Association of Perinatal Medicine Framework for Practice structured the day; core content included the underpinning concepts of Family Integrated and Psychologically Informed Care.
- A range of methods including lectures, group discussions and workshops were utilised.
- 10 study days were held across the region to facilitate access for staff between January 2023 and February 2024.

Parents as Partners in Care: An introduction to Family Integrated Care

- The history, benefits and evolution of FiCare
- Family Experiences
- Why do we want to encourage parents as partners in care?
- BAPM framework for practice
- Relational practice in the neonatal unit
- Roles and responsibilities of health care professionals
- Myth Busting



Results

- Over 200 staff attended; all units and professional roles were represented including Paediatric Intensive Care, nursing, midwifery, medicine, allied health professions, psychology and pharmacy.
- Attendee feedback was excellent (4.8/5 average rating).
- When evaluating the impact of the training, the authors concluded many attendees had prior understanding of FiCare; the programme did not reach the audience required to significantly influence cultural change.

Conclusions

- Staff feedback informed the evolution of this programme.
- Resources were produced to support local teams to deliver education.
- Replication as universal education for all staff may facilitate the implementation of Family Integrated Care. WMPN are implementing a new education strategy which integrates the biopsychosocial model into all future offerings. Progressive cultural change and achievement of national accreditation schemes will evidence the effectiveness of this work.

STAFF WHO WORK TOGETHER, train together:

A multiprofessional approach to teaching on the Foundations in Neonatal Care Course within the West Midlands.

AUTHORS
Randell L,^{1,2} Francis M,^{1,2} Evans D,¹ Causier J,¹ Parnell K,¹ Raiman C¹

AFFILIATIONS
West Midlands Perinatal Network¹
Keele University²



The authors acknowledge the support of the wider West Midlands Perinatal Network team and the Module Lead at Keele University in the development of this work.

Aims

To fully integrate the biopsychosocial framework throughout the FINC course.

Methodology

- A Multiprofessional faculty including Neonatal Network Educators, AHPs, Psychologists and Care Coordinators
- Formulated case discussions were written by the MDT faculty, underpinned by the philosophies of psychologically informed, family integrated, developmental care and clinical skills
- Case discussion scenarios were shared with students asynchronously
- Case discussion feedback was facilitated by an MDT approach
- Key learning points were collected and shared with students post session

Results

Written feedback and user satisfaction about the quality and content of the case discussions indicated they were well received by the students. Constructed reflections were given to help develop this approach for future iterations.

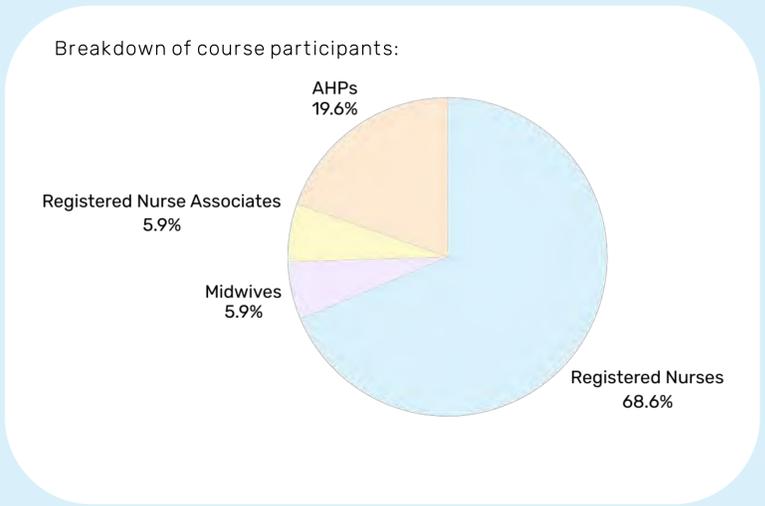
On reflection, the faculty also reported increased satisfaction due to improved group engagement, meaningful discussions and collaborative working within the Neonatal Network team.

Background

The Neonatal Network Foundations in Neonatal Care (FINC) course is a well-established programme accredited by Keele University. Increasingly neonatal care is being delivered by a multidisciplinary team including Nursing, Medical, Pharmacy, Allied Health and Psychological professionals. To educate this growing, diverse workforce presents an opportunity to bring together knowledge from a broad range of perspectives to develop a high quality, evidence-based, efficient and integrated approach to learning. As a multidisciplinary network team (MDT) we made changes to the FINC course to accommodate this developing need, ensuring access to education that underpins clinical skills and practice with therapeutic concepts from developmental, family integrated, and psychologically informed philosophies of neonatal care, in a biopsychosocial framework. To support this framework, case discussions were used.

Feedback Did you find the case study sessions valuable?

- "Communication and Multidisciplinary Team working is essential"
- "Yes, they were a valuable way to share ideas and discussion. Some of the discussion may have been slightly repetitive, but always good to reiterate points"
- "I thought the case studies were really interesting and the discussion was in a good format"
- "They were amazing, related to real life events"
- "Having a multidisciplinary team is pivotal"



Conclusions

- Student feedback was largely positive and included reflections for improvement; these were to focus on two case discussions following one baby and their family and for the discussions to take place in a face to face forum. These changes have now been introduced into the next iteration of the course.
- Students recognise the value to learning within an MDT environment and having MDT educational facilitators.
- Case discussion was perceived as a valuable tool to encourage learning.
- Continued evaluations will take place to further support the development of this approach.

Network Team Reflection

Open discussion encouraged an environment of effective multiprofessional learning. The planning and delivery of the approach has improved working relationships within our own multidisciplinary team. The case discussion based approach allowed us to integrate different ideas together in a way that had previously been a challenge through more didactic teaching formats.

RELATED LITERATURE

Adams, E. Harvey, K. Sweeting, M. (2022) *Neonatology GIRFT Programme National Specialty Report*. GIRFT. www.gettingitrightfirsttime.co.uk

Cookson, J. Francis, M. (2023). *Foundations in Neonatal Care: multidisciplinary approach to training and neonatal workforce*. Infant.19(4) 120-122. London.

Independent Maternity Review. (2022). Ockenden Report – Final: *Findings, conclusions, and essential actions from the independent review of maternity services* at the Shrewsbury and Telford Hospital NHS Trust .

Improving Neonatal UNICEF Baby Friendly Initiative (BFI) in-house staff education across the West Midlands

– a service development project

AUTHORS
Fox C¹, Causier J¹, Raiman C¹, Clarke S¹, Parnell K¹, Harris-Scanlon B¹, Olson V²

AFFILIATIONS
1 West Midlands Perinatal Network
2 Neonatal Unit, Worcester Acute Hospitals NHS Trust

The authors acknowledge the support of the wider West Midlands Perinatal Network team



Background

- Infant feeding, BFI and Network leads in the West Midlands identified significant challenges with access to high quality, standardised Neonatal BFI educational resources for in-house training. Releasing staff to attend training from clinical duties was also a barrier to progress through the accreditation process.
- Of 14 neonatal units in the West Midlands, only 2 had achieved full BFI accreditation.

Aims

- To standardise and improve the quality of staff BFI education resources.
- To support and enhance progress through the accreditation process.
- To improve breastmilk rates, outcomes and consistency of care for families across the West Midlands.

Methodology

- A multidisciplinary group including the Neonatal Network Care Coordinators, Allied Health Professionals (AHPs) and Trust Infant Feeding/BFI leads co-produced a bespoke one-day neonatal specific training package for neonatal unit staff.
- The presentations, videos and narrated sessions were compliant with mandatory BFI curriculum content reflecting Neonatal Network-wide and local care practices.
- 2 services worked collaboratively across the Local Maternity and Neonatal System (LMNS) footprint to deliver their education together where possible.

Results

- 6 neonatal units trained almost 400 staff using the new education package over a 12-month period
- Written feedback and user satisfaction with the quality and content of the resources was excellent and progress through to Stage 2 accreditation accelerated in all participating units

Feedback

The most interesting study day that I have ever been to!

An excellent and informative day, so relevant to practice. Was great to share ideas and learning with colleagues from another unit

It has made me more aware of the importance of including the parents as much as possible into their baby's care. Parents should be considered when making any changes as they might want to be present

Was a lovely session and feel privileged to have been able to attend.

A very informative & enjoyable study day which will help me in my role in TCU. Thank you.

Conclusions

- Staff audits will inform any amendments to the resources and on-going success in achieving full BFI accreditation will assess the effectiveness of the training.
- This model could be replicated nationally to improve and standardise Neonatal BFI education.

Network Team Reflection:

Co-production across the multi-disciplinary Network and clinical teams has ensured the development of a high-quality, dynamic and responsive resource, that reflects both the BFI Neonatal Standards and local care practices.

Related literature

- Unicef UK (2022) *Unicef UK Baby Friendly Initiative - Guide to the Neonatal Standards*
- Adams, E. Harvey, K. Sweeting, M. (2022) *Neonatology GIRFT Programme National Specialty Report. GIRFT. www.gettingitrightfirsttime.co.uk*
- NHS England (2019) *The NHS Long Term Plan. Available at: www.longtermplan.nhs.uk/publication/nhs-long-term-plan*

CAPTURING PARENT EXPERIENCE

Using Emotional Touchpoints to facilitate Appreciative Inquiry (AI) conversations with families on the Neonatal Unit

EXPERTS BY EXPERIENCE

AIM: to capture meaningful parent experience

- Use AI Emotional Touchpoints tool
- Take place during the hospital stay
- Conversation based rather than form filling
- The family/individual pick the topic (touchpoint) card
- The blank card allows them to pick a different topic if they wish
- They then select words (or images) to help talk about their chosen topic
- Together explore what factors contributed to this eg environment, resources communication, behaviours
- Notes are taken and stored



LISTENING IS AN ACTION ITSELF

Parents' reflections on AI conversations

"I thought that I was doing it for the unit but really it helped me!"

"It helped me to find the words to describe parts of my experience that I have not said out loud until now"

"I can see how far we have come, we spend so much time living moment to moment, feed to feed, test to test, it was good to pause and think back"

"Having the space to talk really helped me to then share it with others too"

What happens next...

CELEBRATE

- ★ Staff certificates with parent words
- ★ Posters with positive stories on
- ★ Included on Trust Patient Experience Platform
- ★ Governance Reports

"So lovely to hear I made a difference to parents. Because it is more than just thank you it helps know specifically what to keep doing more of."

"When you read things from the parent perspective it makes you really think, I will do some things more intentionally now I know how much they mean."

WHAT WE FOCUS ON GROWS

COPRODUCTION

These new ideas help to redesign current resources and ways of doing things and create new ones too

Some examples of this include: new cot boards, admission bag & leaflet, information padlet and Journey Folder.



EXPLORE

In staff meetings, workshops and in parent sessions reflect on specific or themed feedback using other AI tools eg Stories Have Legs



What stands out for you?

What are you wondering about?

What could we hope for?

What one small thing will you do differently?

Generates new ideas and possibilities



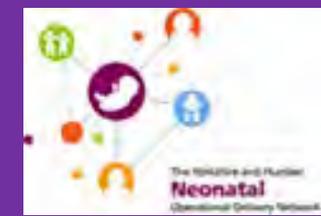
SHARE What Matters To Me

To help the team to see things through the eyes of the parents: shared in newsletters, educational videos, themed posters & word clouds



CONCLUSIONS : This is a safe, replicable and effective approach to building a service responsive to service user needs. Capturing parent feedback in this way helps to celebrate good practice, enables genuine coproduction and improves the care and experience of neonatal families. **Next steps:** Include siblings. Increase accessibility. Introduce audio capture.

Diane Gray
Family Integrated Care Lead
Neonatal Unit, MKUH
diane.gray@mkuh.nhs.uk



'All Wrapped Up' Package

Donna Redfern, Neonatal Care Coordinator
Yorkshire and Humber Neonatal Network, Family Care Team (donna.redfern4@nhs.net)

AIM

Produce a parent resource designed to **encourage** and **empower** parents to be present **before, during** and **after** potentially painful and/or stressful events. Providing them with the **knowledge** and **skills** to comfort and support their baby.

- Focus on **Wrapping Techniques**
- Improve **consistency** in practice
- Encourage **individualised** Neurodevelopmental Care

METHOD

Meaningfully Co-produced by the ODN Family Care Team, Parents, AHP's and Colleagues across the Network

Shared with the **Co-production group** for comments and feedback

Live video demonstrations of wrapping techniques with volunteer families within our Neonatal Units

CONTENTS

- Nest building and positioning
- Other non-pharmacological ways to support before during and after painful procedures/experiences
 - General wrapping
 - Wrapped bathing
 - Wrapped weighing
 - Wrapped cannulation
- Support during ROP & LP procedures

QR CODE/LINK TO PACKAGE



[Yorkshire & Humber Neonatal Families - All Wrapped Up Package](#)



FEEDBACK

57% of parents and **58%** of staff found the resource useful and easy to use in a recent survey

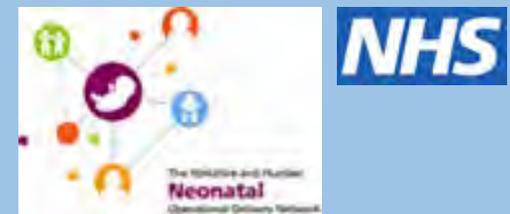
Parent feedback:
"This was very useful...I think it's a brilliant idea"

Staff feedback:
"great resource to increase parents and staff awareness of comforting techniques"

A mechanism for embedding and monitoring true FiCare - Individual Unit Tracker Document and Evidence Key

Donna Redfern, Neonatal Care Coordinator

Yorkshire and Humber Neonatal Network, Family Care Team (donna.redfern4@nhs.net)



AIM

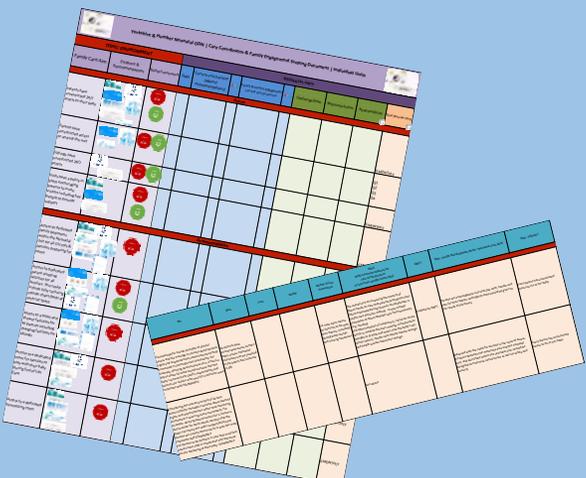
Produce a staff resource designed to provide units with a mechanism to identify, implement and monitor progression of true FiCare

- Clearly demonstrate Family Care aims and recommendations to support improvement plans and business cases
- Align with the BAPM FiCare framework five key principles
- Identify crossover within the current recommendations
- Illustrate individual unit current provision & RAG score based on recommendations
- Acknowledge unit challenges and provide a QI section for strategic progression; providing units the opportunity to break each aim down into manageable pieces
- Celebrate and share success to encourage consistency across the region
- Highlight the different approach between the Care Coordinators and Parent & Family Engagement Lead
- Provide a structure for monitoring progression across the region

METHOD

Tracker documents and Evidence key are accessible on the Y&H ODN Neonatal NHS Futures platform by key members of staff on each unit, along with the Family Care Team - Providing the opportunity for communication, strategic support and guidance.

The Family Care Team connect with unit teams on a regular basis to review progression and provide ongoing support. These include unit visits and virtual regional wide drop-in sessions for staff to share ideas and challenges and discuss improvement plans.



RESULTS

Individual units utilise the document to monitor their progression, identify areas of priority and plan improvements.

The Family Care Team use the documents to collate data on a quarterly and annual basis to track network progression and identify regional areas of priority:



The Northern Neonatal Network have adopted this same mechanism to support FiCare progression, providing the opportunity for collaborative working and consistency for babies and families across both regions

FEEDBACK

- “This document is shared at senior nurse meetings, everyone has an awareness and understanding of what and how it works”
- “Staff awareness and practicality to put practices in place”
- “It makes us aware of changes we need to get better”
- “The tracker helped me when I stepped in to understand where the focus’ are relating to the wider picture. It has helped me to evidence changes”

'Our Neonatal Journey'

- Parent competency/confidence



Donna Redfern, Neonatal Care Coordinator

Yorkshire and Humber Neonatal Network, Family Care Team (donna.redfern4@nhs.net)

AIM

Produce a document to accompany the 'Our Neonatal Journey' parent resource which will remain in the baby's medical record and provide the following:

- Evidence of **education** and recording **parental competencies and confidence**
- Ensure all parents and families are supported to be **partners in care**
- Encourage a **holistic approach** for families to progress at their own pace
- Ease **transition** with **transfer**
- Improve **consistency** across the Network

METHOD

Meaningfully Co-produced by the ODN Family Care Team, Parents, AHP's and Colleagues across the Network

Each section is accompanied by a **Staff Crib Sheet** and where necessary, a **Parent/Carer Learner Pack** to direct education

Shared with the **Yorkshire and Humber Transport Service (EMBRACE)** to aid transfer between units

Launched across the Network **July 2023**

CONTENTS

- The document clearly identifies the difference between **Confidence** and **Competence**:

Competency- the nurse must observe a parent/carer performing the caregiving activity for them to be assured that the parent/carer is able to carry out a specific task, safely. This section must be signed by a staff member before a parent can do these tasks independently.

Areas within the package:

- Administration of medicine
- Nasogastric Tube Feeding
- Preparation and storage of feeds



Confidence- staff can sign to say that they have had a discussion, provided information or a demonstration of a caregiving activity with a parent/carer. Parents/carers can also sign when they feel confident, and it will be up to the parent/carer to decide when this is achieved

Areas within the package:

- Positive touch & comforting techniques
- Monitoring your baby
- Wrapping techniques
- Safe sleep
- Basic Life Support



- Mapping**- Dedicated section within the document for staff identify whether they have referred to Regional or individual trust policies/guidelines, or manufacturer's instructions to aid seamless transition between units.

QR CODE/LINK TO PACKAGE



[Yorkshire & Humber Neonatal ODN - NHS Networks](#)



Elaine Wood, Francesca Carey, Martha Jones, Ebony Blewer, Jade McDonald, Jessica Park, Claire Strauss, Iona Gilmour, Paul Cawley, Evelina London Children's Hospital

Background:

Information sharing between family and staff is critical in FICare. Parents have unique perspective on their infant's and their own needs. Multiple factors prevent parent presence 24 hours a day. Sharing information is thus critical but can be lost in medical records or shift handover.

Methods:

Through collaborative co-design between parents a bedside A4 laminated template was produced (figure 1a) to record information. A secondary process of qualitative and quantitative review (spot audit and interview) led to iteration and refinement. The boards were proudly named "This is us" - reflecting their role in projecting the family.

Aim:

To create an easy to use, accessible bedside tool to enhance cotside information sharing for when parents cannot be at the cotside.

Results:

Phase 1 audit:

66% of infants in ITU (n=15), 38% in HDU (n=8) 100% in SCBU (n=4) had 'This is Us' board present at cotside.
 In use at bedsides: 50% ITU, 66% HDU and 25% SCBU.
 Only 15% of boards had a pen, likely contributing to low use.

Inconsistent cotside placement: the 17 boards in use were found in 12 different cotside locations.

Phase 3 design (Figure 1b) has bigger boards, brighter colours and pen clips to facilitate use. The QI cycle continues.

Conclusion:

Families have valuable information to share about themselves and their baby but varying factors prevent presence 24 hours a day. We present an easy to use cotside tool to facilitate communication. We need to overcome practical challenges to embed implementation.

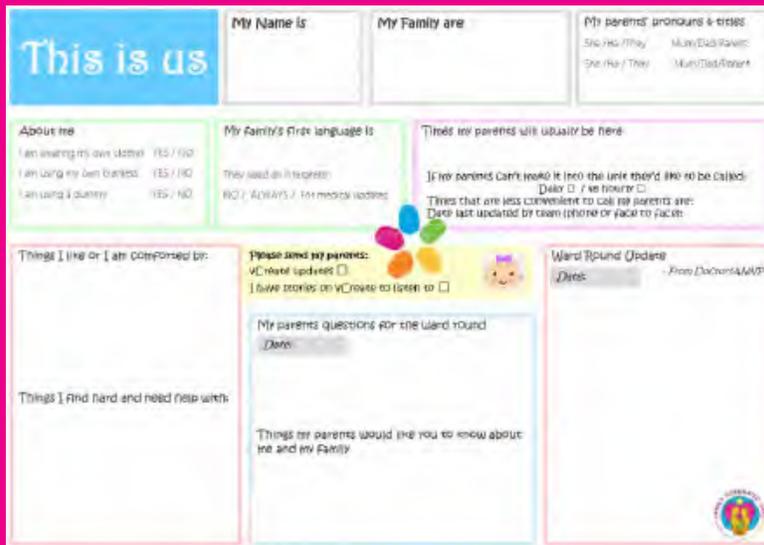


Figure 1a

Parent Feedback

"It has helped me to be involved in my baby's care"

"I feel reassured that staff know how to support my baby when I'm not there"

Figure 1b



Assessment of Knowledge, Attitudes, Practices and Needs of Parents of Preterm Babies Post Discharge from NICU

Authors: Jamal El Eid, PhD student, Salim Adib, MD., DrPH, Lama Charafeddine, MD, Bernard Gerbaka, MD

Background and Rationale

- Preterm births account for over one million neonatal deaths worldwide.
- The prevalence of preterm births in Lebanon is reported approximately 9.6%.
- They need complicated and expensive follow-up and specialized care after discharge.
- Evidence on the knowledge, attitudes, and practices of preterm infants' parents related to their infants' direct and indirect care is limited.

Objectives

- To assess the knowledge and practices of parents in caring for their preterm infants at home and explore their experiences and perceived needs.
- To explore the direct and indirect costs of caring for a preterm baby post-discharge.

Methods

Descriptive study using quantitative and qualitative methods

Setting and Target Population



Public and private hospitals in Beirut and Mount Lebanon.



Lebanese Parents of preterm babies

Tools



Online Survey



Interview Cost Log

Survey

• Five major sections:

- **Knowledge** of basic preterm babies' care
- **Sources** of information
- **Self-Confidence** to handle and care a preterm baby
- **Practices** of parents post discharge from NICU
- **Demographics:** Age, Education, Household Crowding Index, Perceived Family Income.

Semi-Structured Interview

- Experience with preterm birth
- Challenges and Fears
- Predischage education and preparedness
- Perceived Needs
- Cost of care for the preterm baby after discharge

Preliminary Results



70 families completed the survey

between January and September 2024

10 families took part in the interview

Preliminary Results

Average of completed gestational weeks	31.6
Average Length of Stay in NICU (days)	28.7
Mean age of mothers 32.6 (years)	32.6

- 100% of parents received care instructions
- > 50% of parents reported insufficient care instructions and need for additional information.
- 26% are NOT confident handling preterm infant at home.
- ~63% are willing to attend education sessions about preterm infant care.

Implications & Plan of Action



Generate evidence on the current coping situations of preterm infants' parents after discharge from the NICU.



Continue conduction of interviews until data saturation.



Continue the quantitative survey to recruit at least 250 families.



Develop and disseminate parents' educational tool.

Antenatal Counselling for Expected Preterm Delivery: The Parent Perspective

Lawson J, Winton M, Sayer K, Fraser C, Barker L, Williams T

Background & Aims

There is a paucity of evidence regarding the parent perspective of antenatal counselling, particularly within the UK population.

Our aim was to explore the parent experience of antenatal counselling for expected preterm delivery and to understand how clinicians can align their practice with parental needs.

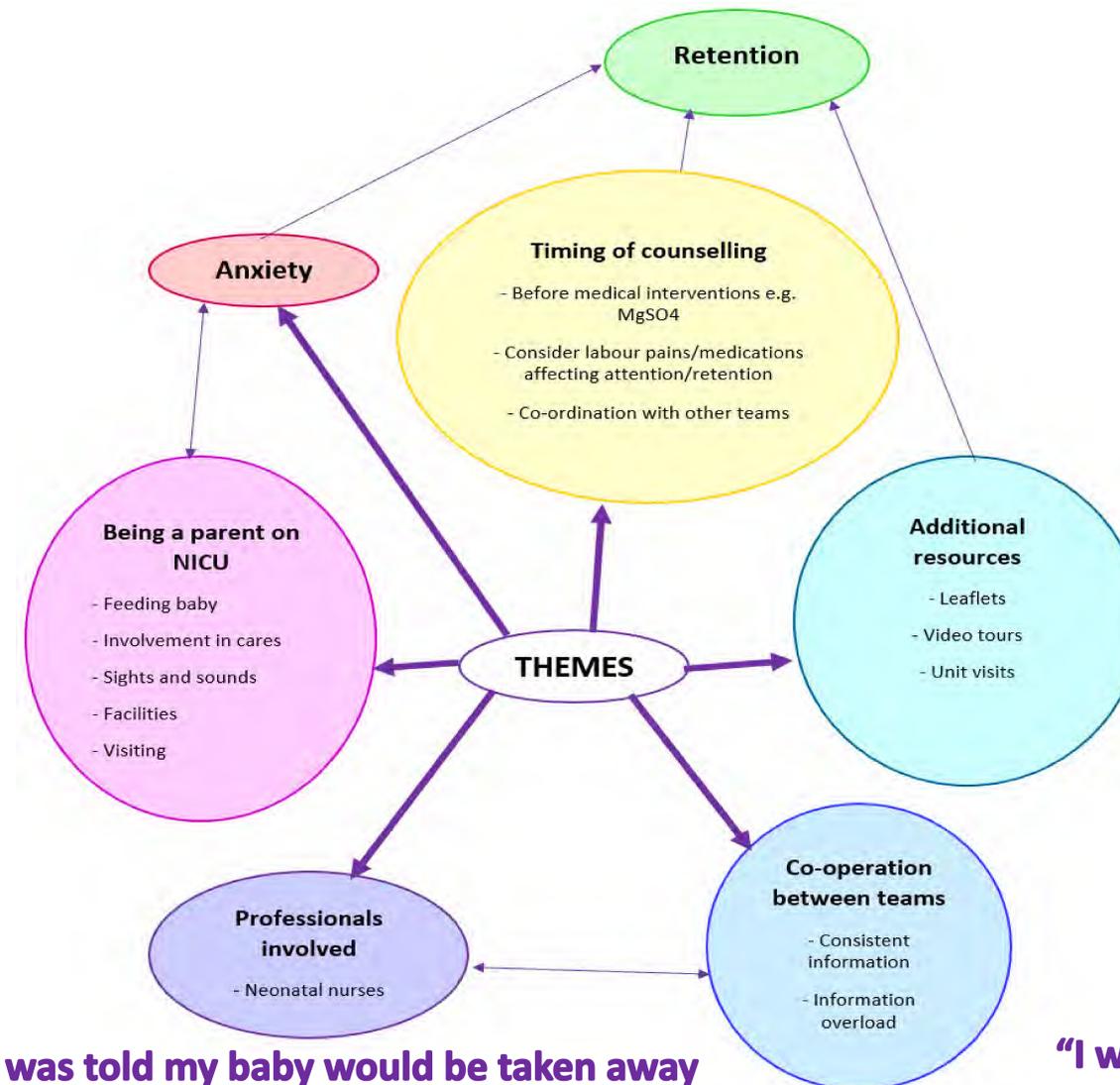
Methods

A prospective questionnaire-based study was conducted at the Jessop Wing in Sheffield, UK. Parents of babies born between 24 and 34 weeks gestational age were recruited between days 7 and 10 after delivery and returned their questionnaires by day 14. A thematic analysis was carried out.

“We got conflicting information about colostrum [from the neonatal and obstetric teams]... this generated quite a lot of anxiety for us about not doing the best for our baby”

Conclusions

Antenatal counselling is valued by parents as a source of information and reassurance. Clinicians can modify their practice to better address parental needs. This includes timing the consult carefully and tailoring the content to the individual, including using additional resources. They may consider inviting members of the multidisciplinary team, particularly neonatal nursing staff, to join them to discuss the non-medical aspects of the neonatal journey.



“I was told my baby would be taken away from me and taken straight to the NICU.”

“I [would like them to] tell you what the room would be like. Very overwhelming.”

“We feel it would be useful to have an experienced neonatal nurse included to discuss care of babies once arrived in NICU”

“I would have liked to know... the process of the room when going in and how overwhelming it can be”

“I can’t remember much about the conversations, I was in severe pain, on medications, gas and air”

Results

18 sets of parents were approached for study entry, of which 16 consented. 10 questionnaires were returned. The thematic tree highlights the main themes identified from the responses.

The most notable theme was how under prepared parents felt for looking after their baby on the neonatal unit. They felt that neonatal nurses may be better placed than medical staff to provide this aspect of antenatal counselling. They also felt that careful consideration should be given to the timing of counselling. They would like it to be coordinated around visits from other teams, and suggested that when delivery is imminent, discussion of less urgent topics could be delayed until after delivery.

“We appreciate the time taken to discuss things with us, also allowing us to raise any questions”



Enteral Tube Feeding in Partnership: Introducing FiCare to the neonatal units at Children's Health Ireland.



Ms Jenny Dunne^{1,2}, Dr Margaret Moran^{1,2}, Ms Heather O'Tuairisg²

1 Department of Neonatology, CHI at Crumlin
2 Department of Neonatology, CHI at Temple Street

Background

We were supported by the RCPI to use a Quality Improvement approach to introducing FiCare to the neonatal units at Children's Health Ireland (CHI). Improvement science tools dictated our first step: empowering parents to tube feed their baby in partnership with the healthcare team.

Aim

By June 2024, 80% of neonates who require tube feeding will receive their feeds from their parents during their hospital stay, following effective education and training, in partnership with the healthcare team using the FiCare model.

Methodology

A survey of parents identified a lack of parental involvement when an infant is fed via an enteral tube¹. The 4 pillars of FiCare provided the scaffolding and framework on which to build this quality improvement. A tube feeding parental competency document was created and in use from February 2024. Data of the numbers of parents assisting with tube feeding pre and post FiCare interventions from January to June 2024 was collected.

Reference: 1..van Veenendaal NR, Auxier JN, van der Schoor SRD, Franck LS, Stelwagen MA, et al. Development and psychometric evaluation of the CO-PARTNER tool for collaboration and parent participation in neonatal care. PLoS One. 2021 Jun 9;16(6):e0252074. doi:10.1371/journal.pone.0252074.

Results

There has been a positive increase (**from a median of 8% to 47%**) in the number of parents assisting with tube feeds from January to June 2024.

Follow up staff survey:

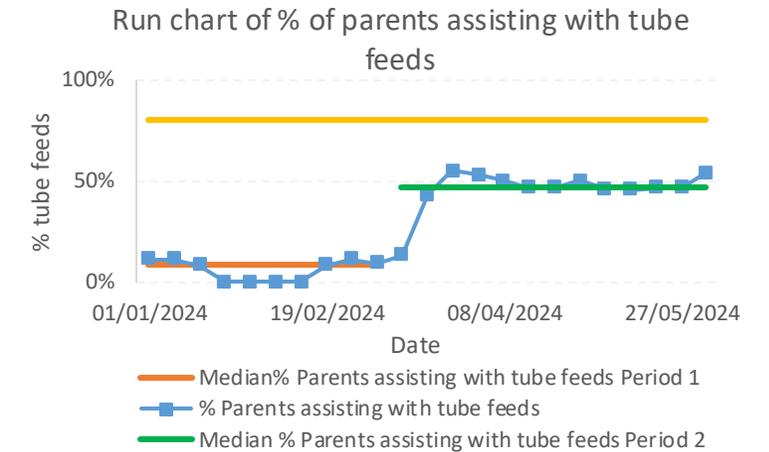
- 70% of staff said they're Knowledge of FiCare had increased
- 100% staff are interested in FiCare on the neonatal unit
- 20% of staff requested further education and training.

Parent Feedback:

'I was trained by the nurses to place an NG tube for my daughter. I found it really hard at the start and it took a few tries to get it right, but it has been so worth it in the long run. The nurses were always very patient and encouraging with me. They answered any questions I had and explained that although my baby would feel discomfort during the process, it would not hurt her.'

Conclusion

This project has been successful in introducing FiCare to the neonatal units supported by a FiCare Steering group and the recruitment of FiCare champions.



Background and Aim

- In Korea, most neonatal intensive care units (NICUs) face challenges such as limited space and a shortage of healthcare providers.
- As the importance of Family-Centered Care (FCC) in the NICU becomes more apparent, various efforts are being made.
- This study aims to develop FCC protocol for parents of premature infants admitted to the NICU.
- The goal is to provide healthcare providers with guidelines to implement FCC.

Materials and Methods

- The protocol was developed using the five stages of the ADDIE model.
- Literature reviews and individual interviews with parents of premature infants identified key components for FCC.
- This draft was refined through expert validity verification
- Our center planned to develop and implement of FCC protocol for the period from May to October 2024 (Figure 1).



Figure 1. Development and Application of a FCC Protocol for Premature Infants and their families

Results

- Literature review and existing program analysis highlighted the importance of emotional and multidisciplinary support for families.
- Interviews with parents revealed a lack of emotional and multidisciplinary support in NICU care, and the need for specific guidance and detailed education on implementation of FCC.
- The expert validity test yielded a content validity index of 0.99.
- The revised protocol (Table 1) consists of 33 items across three domains: a Parents' bill of Rights, Guidelines for Healthcare Providers, and a Stage-Specific Guidelines for FCC interventions.
- Detailed practices for each item, such as noise reduction, light control, and other developmental care are being developed.

Results

Table 1. Family-Centered Care Protocol for Premature Infants and Their Families

Categories	Programs	
Parents' Bill of Rights	1 Parents have the right to have their family's diversity (religion, culture) recognized and their opinions respected.	
	2 Parents have the right to form an equal partnership with healthcare providers.	
	3 Parents have the right to receive support from healthcare providers in making decisions and participating in newborn care.	
	4 Parents have the right to receive sufficient information from healthcare providers.	
	Guidelines for Health Care Provider	5 Parents are respected as the primary caregivers in the NICU.
		6 Parents are treated as part of the care team, not as the visitors, and always welcomed.
		7 Healthcare providers eliminate bias and understand the family's diversity when providing care.
	Guidelines for FCC interventions	8 Healthcare providers maintain open and comprehensible communication, providing consistent information.
		9 Healthcare providers help parents acquire the necessary caregiving skills.
At the time admission		10 Emotional support is provided to parents dealing with unexpected births.
		11 Parents receive an orientation about the NICU and its environment using video.
		12 Explanations are provided regarding the tubes and equipment used on the newborn during the first visit.
During hospitalization		13 Information on premature infant conditions and treatments is provided.
		14 Guidance on post-discharge financial support systems for premature infants is given.
		15 Parents are informed about family-centered care and their rights.
		16 Parents are informed about the types of care they can provide to their newborn. (Holding, changing diaper, massage, playing music, storytelling, feeding, Kangaroo care)
	17 Information on breastfeeding benefits, pumping methods, and storage is provided.	
	18 The newborn and environment are kept clean.	
	19 Soft lighting and minimal noise are maintained in the NICU.	
	20 Parents are informed about the types of care they can provide during visitations. (Holding, changing diaper, massage, playing music, storytelling, feeding, Kangaroo care)	
	21 Guidance on infection control, such as screening for infectious symptoms and handwashing, is provided.	
	22 Parents are encouraged to spend as much time as possible with their newborn.	
	23 Healthcare providers help parents understand the baby's characteristics.	
	24 Emotional support is continuously provided to monitor parental anxiety and depression.	
	25 Breastfeeding preferences are respected, and further consultation is provided if desired.	
	26 The benefits and methods of kangaroo care are explained.	
	27 Interaction between baby and parents during kangaroo care is explained.	
28 The discharge time is discussed and decided collaboratively by parents and healthcare providers.		
At the time discharge	29 Parents are encouraged to express their feelings and concerns about premature infant care.	
	30 Challenges after discharge and coping strategies are explained.	
	31 Parents are supported in feeding premature infants.	
	32 Special education (neonatal resuscitation, gavage feeding, oxygen therapy, and stoma care...) and rehabilitation therapy are provided early in discharge preparation.	
	33 Discussions on post-discharge plans (discharge preparations and home environment) and helpful information are provided.	

Results

- Detailed practice for soft lighting and minimal noise
- 1. Quiet time
 - 1-3 A.M.
 - The lights throughout the NICU, except for the central area, are turned off (3 -10 lux).
 - Feeding, blood sampling and other procedures are not performed except for essential treatment.
 - The ward noise level is maintained below 45dB
- 2. Light
 - For infants <37 wks, use an incubator cover that matches each incubator model.
 - Individual lights are turned on only 50% of full brightness when treatment is needed (24 lux vs. 33 lux).
- 3. Sound
 - Target noise level <50 dB with alarm level <65 dB
- Detailed developmental care practice
 - Holding neonates during painful procedures for pain and stress relief
 - Encourage holding neonates by parents during visits
 - Nursing education was provided for the appropriate position (Figure 2).

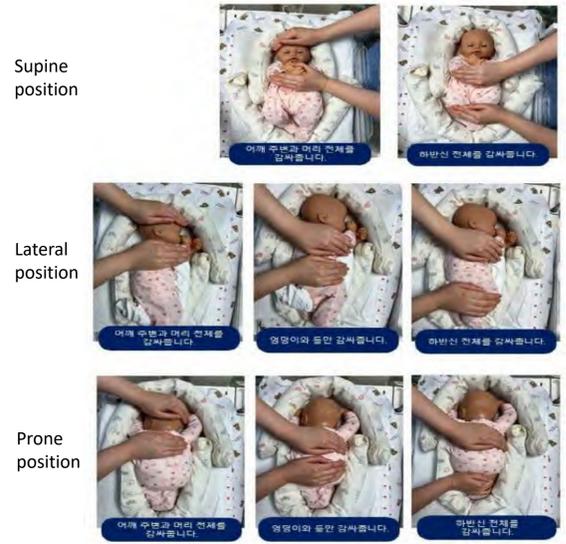


Figure 2. Appropriate positioning while holding the neonate

Conclusions

- The developed protocol standardizes and systematizes FCC in the NICU, strengthening bonds between premature infants and their parents.

FCC Family-centered care, NICU Neonatal intensive care unit

Family-Integrated Palliative Care on End-of-Life in a Tertiary NICU : A Comparative Study and Nursing Perspective

Joohyung Roh¹, Euseok Jung¹, Bo Kyeong Jin¹, Jung Il Kwak¹, Tae Gyeong Kim¹, Kyu Sang Yoo¹, Ha Na Lee¹, Sung Han Kang², Heeyoung Kim³, Hyojin Lee³, Namju Lee³, Kayoung Lee³, Byong Sop Lee¹

¹Department of Pediatrics, University of Ulsan College of Medicine, Asan Medical Center Children's Hospital, Seoul, Korea

²Department of Pediatric hemato-oncology, University of Ulsan College of Medicine, Asan Medical Center, Seoul, Korea

³Department of Pediatric nursing, University of Ulsan College of Medicine, Asan Medical Center, Seoul, Korea

Background

- ❖ In 2021, Asan Medical Center Children's Hospital NICU in Seoul initiated a family-integrated palliative care program for neonates facing end-of-life situations.
- ❖ Aim: To evaluate the impact of the family-integrated palliative care program by comparing end-of-life outcomes before and after its implementation and assess current nursing perspectives on end-of-life care.

MATERIALS & METHODS

- ❖ Retrospective analysis
 - : comparing the rates of DNR(Do not resuscitate) orders
 - : 2018-2020 (pre-implementation) vs 2021-2023 (post-implementation)
- ❖ Fisher's exact test: $p < 0.1$ considered statistically significant
- ❖ Surveys to NICU nurses in 2024
 1. Stress levels of end-of-life care
 - Bereavement Support Stress Measurement Tool
 - (<2: no stress; 2-4:mild stress; >4: severe stress)
 2. Attitudes toward facing death
 - Frommelt Attitudes Toward Nursing Care of the Dying Scale (FATCOD)
 - (<2.5: negative attitude; >2.5: positive attitude)

RESULTS

Figure 1. Study Population

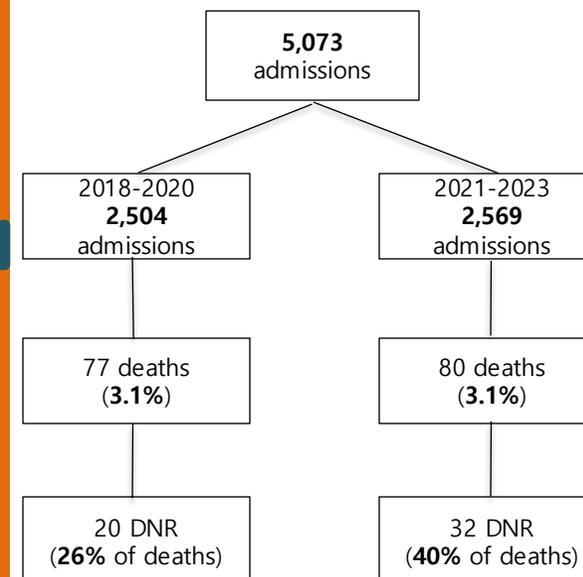


Table 1. Difference of DNR rates before & after family-integrated palliative care

	2018-2020	2021-2023	p-value
Admission	2504	2569	
Death	77	80	
DNR	20	32	.065

- ❖ Surveys from nurses
 - : mild levels of end-of-life care stress (2.68-4.48, mean 3.81, SD 0.47)
 - : positive attitudes towards end-of-life care (1.50-3.58, mean 2.913, SD 0.60)

CONCLUSION

- ❖ Implementation of a family-integrated palliative care program
 - : associated with a significant increase in DNR orders
- ❖ Nurses reported mild stress levels & positive attitudes when providing end-of-life care following the program's introduction → potential improvements in end-of-life care practices
- ❖ Next step: the impact on family experiences

Informing education and knowledge about the enablers and challenges to communication between preterm infants and their parents.

Dr. Julia Petty & Dr. Lisa Whiting - University of Hertfordshire [UH], UK
 & Professor Celia Harding - City & St. Georges University of London, UK



BACKGROUND

RESULTS

CONCLUSION & IMPLICATIONS FOR FUTURE PRACTICE

- Preterm birth is a risk factor for a range of future difficulties & outcomes, including development of speech, language and communication (SLC) needs (Harding et al, 2019) potentially impacting on educational achievements and the ability to engage socially later in life (Green et al, 2021; Harding et al., 2022).
- Learning to communicate with infants in a neonatal unit (NNU) setting is challenging & admission imposes many barriers to effective communication as voiced strongly in previous research by parents themselves (Petty et al, 2019a; 2019b).
- Clear, consistent, and culturally appropriate communication strategies are required (Romeo et al, 2023) so that language-rich environments, through supported approaches including staff/family education, can support parents to learn about, feel confident & sustain positive communication with their infant.
- This area needed exploring further & more deeply to inform resource development in all areas of communication.

- Inconsistent advice as to how to facilitate SLC needs was reported by parents who stated that obtaining information was often difficult.
- Nurse participants recognised the value of helping parents to bond and develop care skills with their infants; interaction and communication were highly regarded as being essential.
- Necessary procedures, including wearing face masks, were seen as prohibitive to developing communication dynamics between infants & parents. Moreover, positive communication between staff and parents was also commonly described as vital but often lacking, bringing in another area to improve on in our ongoing work.
- Nurses agreed that good communication was crucial but were unable to describe what they meant by "communication" from a linguistic perspective (Petty et al, 2024). Both groups agreed that resources, particularly digital in nature, related to necessary interventions to support SLC development in preterm infants, as well as between staff and parents, were needed.

- Daily & skin-to-skin care, while positive and necessary for bonding and closeness, are not themselves communication strategies in the context of linguistic development.
- Therefore, further resources and education are needed by staff & parents to support the development of positive dyadic linguistic relationships in early neonatal life.
- Better training and support resources about early communication, beyond foundation skills, for both neonatal staff and parents, is of paramount importance and is now an area for further research and improvement. This includes parent-staff communication dynamics in the NNU.
- Web-based, digital resources in this area were identified as being required and are now being developed to facilitate this [Figs 1 & 2]. Further funding is being sought.

AIM

- To explore parent and neonatal nurse understanding of the factors that promote or hinder early communication and interaction between preterm infants and parents, to inform supportive educational resource development.

METHODOLOGY

- Narrative interviews investigated parents' and nurses' views of the enablers and challenges of developing infant-parent communication as well as their views on how to support positive and productive early interaction. We also sought to ascertain what support is required to facilitate SLC for infants, parents and staff in the NNU.
- UH & Health Research Authority ethics approval was granted.

Figure 1- What resources are needed.....

- Digital resources, delivered via smartphones, tablets &/or computer devices are needed for evidence-based interventions (Petty et al, 2024; Markkula et al, 2024).
- Reading
- Cue-based care & behavioural assessment
- Narration of bedside activities
- Music, including singing & humming
- Guidance for bedside teaching of parents
- Education & resources for students and staff at all levels
- Guidance for NNU communication and after discharge home.

Figure 2- 'Prematurity and Communication' – The PAC website



REFERENCES

- Green, J., Staff, L., Bromley, P., Jones, L., & Petty, J. (2021). The implications of face masks for babies and families during COVID-19: A discussion paper. *J. Neonatal Nurs*, 27(1), 21-25.
- Harding, C., Levin, A., Crossley, S.L., Murphy, R., Van den Engel-Hoek, L. (2019). Effects of early communication intervention on speech and communication skills of preterm infants in the neonatal intensive care unit (NICU): a systematic review. *J. Neonatal Nurs*. 25 (4), 177-188.
- Harding, C., Whiting, L, Petty, J, Edney, S, Murphy, R, & Crossley, S.L (2022) Infant communication. How should we define this, & is it important? *J. Neonatal Nurs*, 28(6), 452-454.
- Markkula, A., Pyhälä-Neuvonen, R., & Stolt, S. (2024). Interventions and their efficacy in supporting language development among preterm children aged 0-3 years-A systematic review. *Early Human Development*, 106057.
- Petty J, Jarvis J, Thomas R. (2019a). Understanding parents' emotional experiences for neonatal education: A narrative, interpretive approach. *Journal of Clinical Nursing*. 28(9-10), 1911-1924.
- Petty J, Jarvis J, Thomas R. (2019b). Listening to the parent voice to inform person-centred neonatal care. *Journal of Neonatal Nursing*. 25(3), 121-126.
- Petty, J., Harding, C., Whiting, L. (2024). Exploring Parental Perspectives of Enablers and Barriers to Communication with their Preterm Infants: A narrative study. *J Child Health Care*, In Press.
- Romeo R, Pezanowski R, Merrill K, Hargrave S, Hansen A. (2023). Parent and staff perspectives on the benefits and barriers to communication with infants in the neonatal intensive care unit. *J Child Health Care*. 27(3):410-423.

With sincere thanks to the Burdett Trust for Nursing for funding this research project, the NHS Trust staff/gatekeepers for enabling access to our participants and to our Parent Advisory Group (PAG) for their invaluable help and advice.

•IMAGE CREDITS (Creative Commons licences)
 •CC BY-NC-ND 2.0 DEED
 •CC BY-SA 4.0 File:MotherKMC.jpg
 •CC BY-SA 2.0 DEED

Parents Supporting Parents: the Coffee Break Card Initiative



Presenter: Karen Bong

NICU graduate parent
NICU Family Support Specialist
Family Advisory Committee Chair
Sunnybrook Health Sciences Centre
Toronto Ontario Canada

BACKGROUND: Current NICU families benefit from additional support that is designed and delivered by graduate NICU families.

AIMS: Our Family Advisory Committee (FAC) wanted to deliver additional support to families that:

- encouraged a feeling of human connection,
- encouraged families to take a break from their baby’s private hospital room,
- enabled mental and physical self-care,
- provided helpful contact with grad families,
- delivered support in a way that families felt was safe from the risk of infection,
- was received on each family’s schedule,
- helped as many families as possible.



Card front



Inside message



Card back

METHODOLOGY: After discussion among the FAC and then consulting our NICU social work team, we developed a family support initiative called the Coffee Break Card.

Graduate family outreach can inspire hope, reduce isolation, and encourage wellbeing in current NICU families.

**Lemonade Time!
NICU grads fundraising for the
Coffee Break Card gift cards**



Sydni Pacan,
born at 26 weeks,
now 7 years old



Emma Penner,
born at 29 weeks,
now 6 years old

“It was extremely helpful. It motivated us to step out from baby’s room, take a long walk beyond the NICU area and provided a chance to re-live a normal life.”

“It means a lot, everything they do, it touches our hearts. That they are thinking about us.”

Quotes from NICU parents who received a Coffee Break Card

THE COFFEE BREAK CARD PROVIDES:

- **Peer outreach:** card has a message of support from graduate NICU parents
- **Support for self-care:** includes a \$5 coffee shop gift card to promote taking a break, getting something to eat or drink
- **Hope:** card graphic design by Lily Steele (right), a Sunnybrook (Women’s College) NICU graduate born at 28 weeks who is now 17 years old
- **A personal touch:** cards addressed to families by their first names and distributed in-person by a NICU grad parent.



On three occasions, Coffee Break Cards were given to all current NICU families (dates in May 2023, January 2024, August 2024).

RESULTS AND CONCLUSION: In August 2024, 100% of recipient families responded positively, expressing thanks or describing the gesture as sweet and nice. Quotes (in the center poster panel) indicate the Coffee Break Card is helping the recipients in the ways the FAC hoped they could support current NICU families.

AUTHORS: Karen Bong, Ebony Anderson-Brown, T. Joseph, Donna Loi, Peggy Ma, Samantha Moore, Peter Obradovich, Chet Rodrigo, Jen Rodrigo, Joshua Shapiro, Vicki Steele, Daniel Tran, and Rita Vivat; Sunnybrook NICU Graduate Parents and FAC Members.

THANKS: to the NICU graduate families who donated time and funds for the coffee shop gift cards and to the Sunnybrook DAN Women & Babies Social Work team for their support.



Meaningful Coproduction in Neonates across Yorkshire and Humber

Project Lead: Karen Williams, Parent and Family Engagement Lead
Yorkshire and Humber Neonatal Network (karen.williams132@nhs.net)



Background

The Neonatal Critical Care Review (NCCR 2019) published a set of actions to improve neonatal care. Action 6 advocates to enhance the experience of families and develop and invest in support of parents. To achieve this in a meaningful way it is crucial that all staff including medical, nursing AHP's, Psychology work co-productively with parents and families to develop and improve neonatal services.

Aim

To develop mechanisms within the Family Care Team to support neonatal staff and parents to work together to co-produce neonatal services from the start and throughout to enhance the experience of parents and families.

Methods

In response to parent and staff feedback and scoping 4 priorities were identified: Access, feeding, comforting your baby and parental voice. It was agreed that a multidisciplinary approach was needed to ensure that co-production was embedded in a meaningful way. Initially this was achieved through virtual topic specific drop-in sessions with staff to facilitate, discuss, share good practice and to understand the challenges faced by units. Alongside this we sought parent feedback through online surveys, 1:1 conversations and focus groups.

Results and Conclusion

A Network co-production group 'The Neonatal Voice' was established in May 2022 to facilitate a mechanism for staff and parents to co-produce services and to provide a layer of governance. Here parents and staff have an equal voice and work collaboratively to ascertain what is needed to improve and develop services. The group has representation from parents and a multidisciplinary team of staff.

The group has a rolling evaluation tool to ensure that co-production is embedded at every stage of the process. Subgroups have now been established to enable topic specific work.

Through the co-production group and its subgroups, the Family Care Team have been able to achieve the facilitation of more effective co-production with all staff groups and parents.



The Development of a FICare Quality Dashboard to support FICare across the London Neonatal Network

Ines da Silva, Laura Kelly and Louise Wells, London Neonatal Network Care Coordinators

Background

Implementing FICare is a top priority in neonatal care in England, and a strategic approach is required to support this process within the largest neonatal network with the highest birth rate in the country.

Aim

The development of a FICare quality dashboard to:

- Highlight and share achievements
- Support gap analysis
- Standardise practices



As awareness of the dashboard grows, units are requesting data to support local FICare business cases and FICare projects; for example **food provision**



The dashboard data is used to **support national reporting** and bespoke data requests



Gap analysis has highlighted variation of **family facilities** across the network and supported the further development of the **network FICare education programme**



Reports have been created to support network and unit business plans and FICare projects; for example promoting **zero separation**



The dashboard has been instrumental in capturing the network's transition to a FICare model, with a **92% completion rate**

Method

Data is collected quarterly by Care Coordinators through meetings with stakeholders. The data is then shared in various formats at relevant forums to support local and regional quality improvements and network strategic planning for FICare workstreams.

Conclusion

The dashboard has supported FICare innovations locally and across the network. It should remain flexible to meet user and stakeholder needs. To sustain it, we will focus on:

- Data value
- Stakeholder engagement
- Feedback



IMPROVING FAMILY EXPERIENCE OF THE NEONATAL TRANSPORT JOURNEY IN SCOTLAND

Dr Rachael Fleming, Ms Lyndsey Stewart, Dr Allan Jackson



ScotSTAR Neonatal Transport Service, Scotland

Background

In January 2024, with the aim of developing a national strategy for standardising family integrated care (FiCare) in Scotland, a FiCare day was hosted by the Scottish Perinatal Network FiCare group. Priority setting by healthcare professionals and parents identified 5 key areas including transition between neonatal units. Parents highlighted transfer of their baby by the neonatal transport team as a particularly worrying and stressful time. With implementation of best start in Scotland, the number of families experiencing transition between neonatal units is increasing. To reduce anxiety surrounding neonatal transfer, it is imperative that families are prepared for their baby's journey and that neonatal unit staff are well-equipped to assist with this.

Aim

To produce an easily accessible video resource familiarising parents and staff with what a neonatal transfer entails.

This project forms part of a wider national project aiming to improve orientation and transition experience for parents.

Method

Pre-event parent questionnaire responses and group discussion in a national working group forum were used to gain insight into parent experience of neonatal transfer.

A draft 'script' was written aiming to address the common questions and themes highlighted by parents.

Video footage of the neonatal transfer process was produced with the aim of outlining what to expect in a neonatal transfer.

Conclusion

This resource will provide easy-to-access, visual information for families and staff in Scotland. The webpage QR code can be easily displayed in units, on transport equipment and provided to remote and rural centres for use in the event of emergency transfer or in preparing families for repatriation of their baby. We hope this resource will go some way to addressing the fear of the unknown parents describe experiencing in relation to transfer of their baby and better equip neonatal unit staff in preparing families for this move.

Results

Valuable insight into parent experience and concerns pertaining to the transfer of their baby were obtained (see below).

Following parent and organisation consultation, a draft 'script' was finalised. Video footage has been recorded and is in the process of being edited. It introduces the ScotSTAR team and their equipment and provides a 'walk through' of what the journey (via road or air) will involve. It aims to answer frequently asked questions.

Launch of the video is anticipated later this month. The resource will be available on the ScotSTAR website as well as the Scottish Perinatal Network unit information webpage.

"My daughter and I had to be apart for the transfer"

"He was ventilated so I was scared that would fall out on the journey"

"I wasn't allowed to travel in the ambulance with my son"

"It was difficult waiting on the ambulance for the move"

"The feeling of what could go wrong in the ambulance was hard"



Fathers' experiences of having a premature baby and their admission to the Neonatal Unit (NNU)

Dr Rupa Rubinstein^{1,2}, Dr John Ho³, Prof Minesh Khashu⁴, Dr Katie Gallagher⁵, Prof Narendra Aladangady^{1,2} 1. Homerton Healthcare NHS Trust; 2. Queen Mary University of London; 3. Barts Health; 4. University Hospitals Dorset; 5. Institute for Women's Health, University College London

BACKGROUND:

Almost 30000 premature babies are admitted to neonatal units (NNUs) each year in the UK¹. Research often explores the experiences of mothers with few fathers seen². Fathers are often present at their premature baby's birth and accompany them to the NNU.

AIM:

To understand fathers' experiences of having a preterm baby and their subsequent admission to the NNU.

METHODS:

Participants: Fathers of babies <33/40 at a level 2 and a level 3 NNU in East London, UK
Data collection/Analysis: Semi-structured face-to-face interview, in a confidential space by a trained researcher (RR). Analysed with inductive thematic analysis.

Timing: Consented in first week of NNU admission
Ethics: Approved by the National Research Ethics Committee(Ref:22/EM/0140)
Registration: Registered with clinicaltrials.gov³.

RESULTS:

23 interviews were conducted at a median (range) infant age of 11 (4-35) days. Median gestational age at birth was 26⁺⁵ (23⁺² to 32⁺³) weeks. 3 Key themes identified are:

Overwhelming and mixed emotions- Fathers reported feeling relief, joy, fear, amazement, worry and excitement at seeing or hearing their preterm baby for the first time.



Feeling lost- Fathers reported challenges in understanding what was happening during the birth of their baby, which were compounded when the baby was transferred to the neonatal unit. Fathers reported feeling torn between staying with the infants' mothers or accompanying their baby.



Predominance of machines and equipment- Fathers reported the plethora of medical equipment used in the care of their baby was overwhelming, being both reassuring and intimidating.



CONCLUSIONS:

Fathers experience a complex whirlwind of emotions after the birth of their premature baby and conflicting priorities as a new father & as a partner. Healthcare staff need to provide clear advice & guidance to support these overwhelmed parents.

REFERENCES: 1. BLISS. Prematurity Statistics in the UK. April 9, 2024; 2. Rubinstein et al. Fathers' experiences of family integrated care (FiCare) in the neonatal unit; a systematic review. Presented at Neonatal Society Spring Meeting: March 10, 2023; 3. Rubinstein & Aladangady. Fathers and Partners in Family Integrated Care Study (TARGET). Clinicaltrials.gov. September 5, 2023.

Womb to Room and Beyond



North West Neonatal Operational Delivery Network: Sarah Fullwood, Samantha Parry, Phillipa Ranson, Jo Marks, Lynette Forsythe, Victoria Walsh, Fiona Pringle, Rebecca Hinton, Ruth Butterworth, Sarah Tandy

BACKGROUND: Early development is pivotal for long-term health and well-being, with the neonatal period being especially critical. Being born early can have profound implications for both babies and their families. The Womb to Room and Beyond series attempts to address these challenges by providing an integrated multidisciplinary (MDT) educational model from the antenatal stage through the delivery room, the neonatal unit and beyond, with a focused lens on neuroprotective care.

AIMS: To identify the impact of being born early and admission to a neonatal unit by delivering comprehensive education focused on all aspects of the baby's development alongside understanding the family's journey and the wider environment. The concept was to empower health professionals in providing them with the education and necessary resources to understand the care we provide has a long-term neurodevelopmental impact.

Methodology Overview:

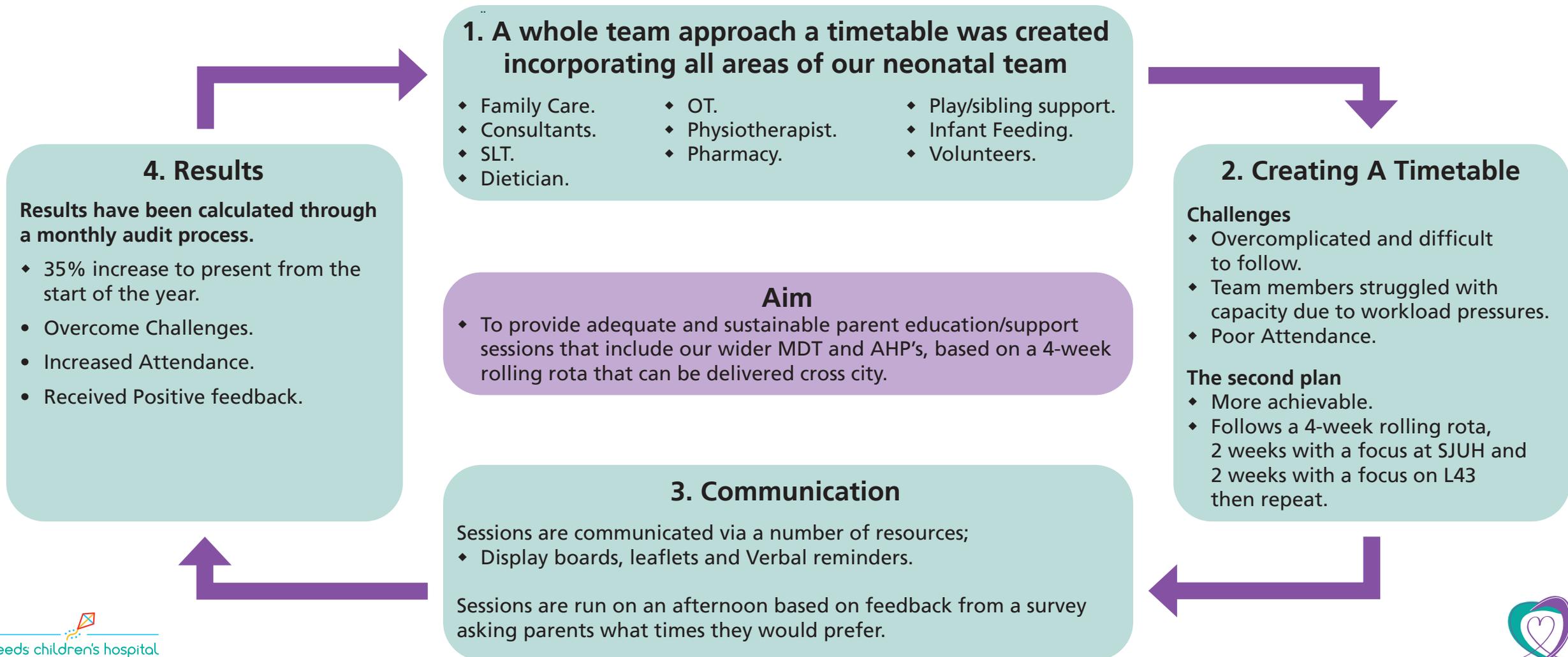
- **5 Webinars:** Focused on multidisciplinary approaches, integrating the parent voice in neonatal care.
- **1-Day Conference:** An experiential event to consolidate and apply knowledge

Results and conclusions- Each webinar was held over 2 dates with a total number of 305 health professionals attending. 68 health professionals attended the conference. Attendees included nurses, AHP's and consultants along with early year practitioners, health visitors and teachers. Positive qualitative feedback received centred on changing and improving practice within Neonatal care and beyond



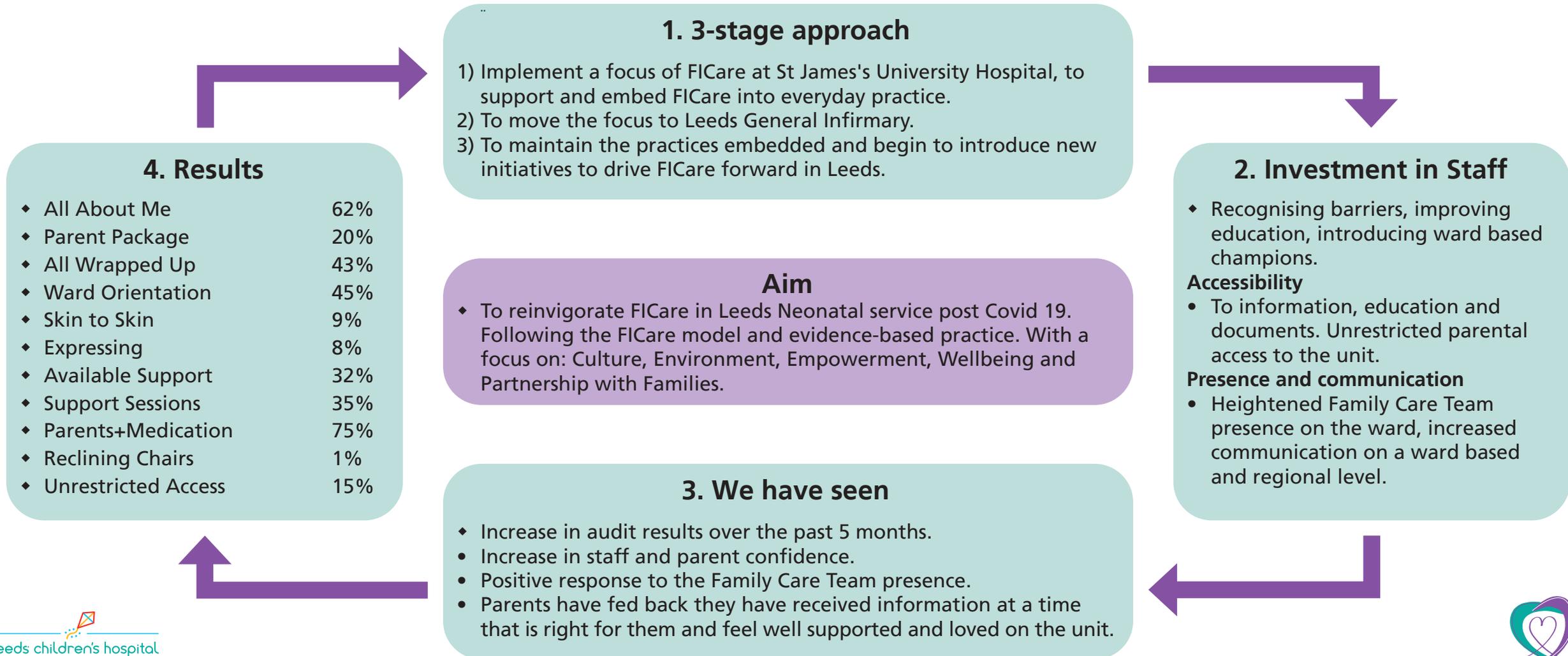
Re introducing parent support/education on the unit post covid 19 pandemic

Sarah McKennell, Laura Mottram, Rachael Hayes and Dr Liz McKechnie - Leeds Teaching Hospitals Neonatal Unit, Leeds, UK



Reinvigorating Family Integrated Care after the Covid-19 pandemic

Sarah McKennell, Laura Mottram, Rachael Hayes and Dr Liz McKechnie - Leeds Teaching Hospitals Neonatal Unit, Leeds, UK



Implementing a parent-focused multidisciplinary developmental care round on a level 3 neonatal unit

Sarah Neilson (Occupational Therapist), Anna Lukens (Physiotherapist), Maya Asir (Speech and Language Therapist), Kerry Engelbrecht (Occupational Therapist), Milly Munn (Physiotherapist), Liam Blundell (Physiotherapist), Elaine Wood (FI-Care Lead Nurse), Dr Andrew Elliot-Smith, Dr Paul Cawley. Neonatal Unit, Evelina London Children's Hospital.

Background: Using an integrated approach of developmental care and family integrated care has demonstrated improved outcomes for high risk infants in the NICU (Alsadaan et al. 2023). Implementation can be challenging due to time constraints, unit culture and parent engagement. Following an increase in therapy staffing, a quality improvement project to implement a multidisciplinary developmental care round was initiated to support holistic infant and family developmental care.

Aim: To empower parents as partners in delivering developmental care for their babies, by increasing their understanding and confidence in developmental care strategies; supported by the implementation of a parent-focused MDT developmental care round.

Methodology:

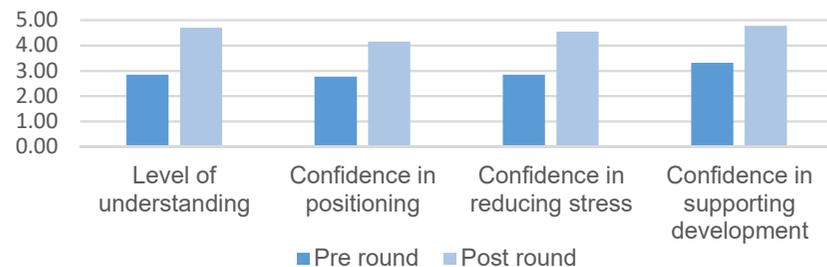
An MDT developmental care round was trialled for 3 months.

This was conducted fortnightly and included parents, occupational therapist, physiotherapist, speech and language therapist, FI-Care nurse, cot-side nurse and doctor.

- 4-6 appropriate babies were identified for each round, based on their admission date, gestational age and medical background.
- Discussions were centred around parental priorities and questions.
- Practical advice, equipment and written information were provided during the round.
- A short questionnaire to gain feedback on parent confidence with developmental care pre and post the round was completed. A 5-point Likert scale was utilised to optimise data collection.

Results: a total of 13 responses were received

Change in parental scores pre and post developmental care round



Feedback from parents:

"I have gained more understanding of how to reduce stress and pain"

"The extra info definitely improves your confidence when looking after a tiny baby"

"Very grateful for the whole team to support, as parents we thought we would have to do it all ourselves"

Conclusions:

- Developmental care round was valued by parents with significant improvements in knowledge and confidence
- Increased frequency of round would enable more babies and families to be seen
- Offers potential opportunities for staff education at cotside
- A second PDSA cycle will focus in increasing staff knowledge and confidence



Supporting Families with Home NG Feeding



Introduction

Our ethos in NICU Ninewells is family integrated care. We support parents to be primary care givers, as early and as often as possible. This means that parents are involved in all aspects of care, increasing their confidence for discharge whilst facilitating earlier discharge.

Objective

We hope to facilitate early discharge with a seamless transition from hospital to home whilst reducing separation anxiety by empowering families to care for their babies with a nasogastric tube insitu at home.

Why?

Babies born prematurely and of low birthweight frequently experience extended stays in hospital. Often this is due to establishing oral feeding, resulting in a growing demand for neonatal cots, increasing the financial impact on services.

Baby Criteria

- Minimum 34 weeks gestation
- Medically fit and ready for discharge
- Good weight gain
- Maintaining own temperature
- Not requiring monitoring
- Tolerating 3 hourly NG feeds
- Managing a minimum of 3 suck feeds in a 24 hour period

Family Criteria

- Willing to give 24 hour care to both baby and NG tube
- Required to complete NG tube feeding teaching pack
- Have completed the re-passing NG tube teaching pack, if appropriate

Findings

- Increase breast feeding rates
- Establish oral suck feeds quicker
- Reduce the amount of time parents are separated from their babies
- Alleviate the pressure put on families to be spending time in NICU
- Ease the financial burden on families during their time in NICU
- Reduce the amount of prolonged hospital stays

Limitations

- Babies may need readmitted if:
- They have poor weight gain
 - They're not making progress with suck feeds
 - Parents are not managing NG
 - Baby becomes unwell

