



Implementing Family Integrated Care: Helping Us Grow (HUG)

Neil Patel

Neonatologist

Royal Hospital for Children, Glasgow, UK

For “Helping Us Grow”





From *Mother Ship* by Francesca Segal

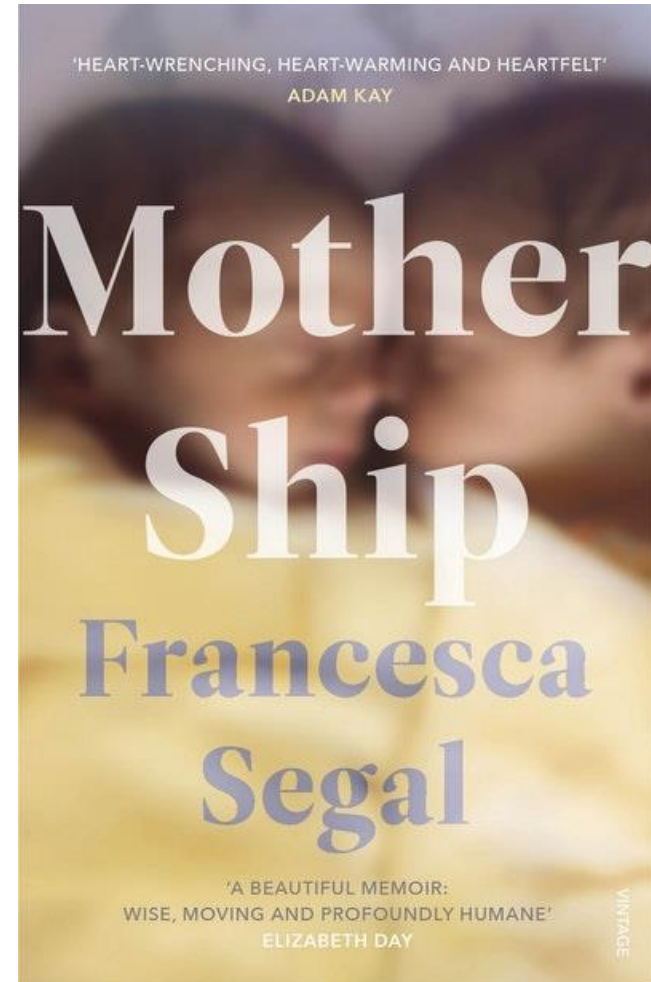
Chatto and Windus, 2019

[the ward round]..

But my children do not appear to need mothering. Instead they need sophisticated medical intervention.....

As they talk, a fogged half-comprehension clarifies into something solid, a single sentence, like water frozen instantly to ice: *I am unable to care for my children.*

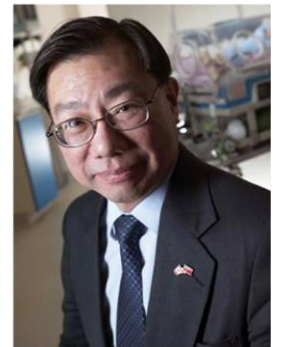
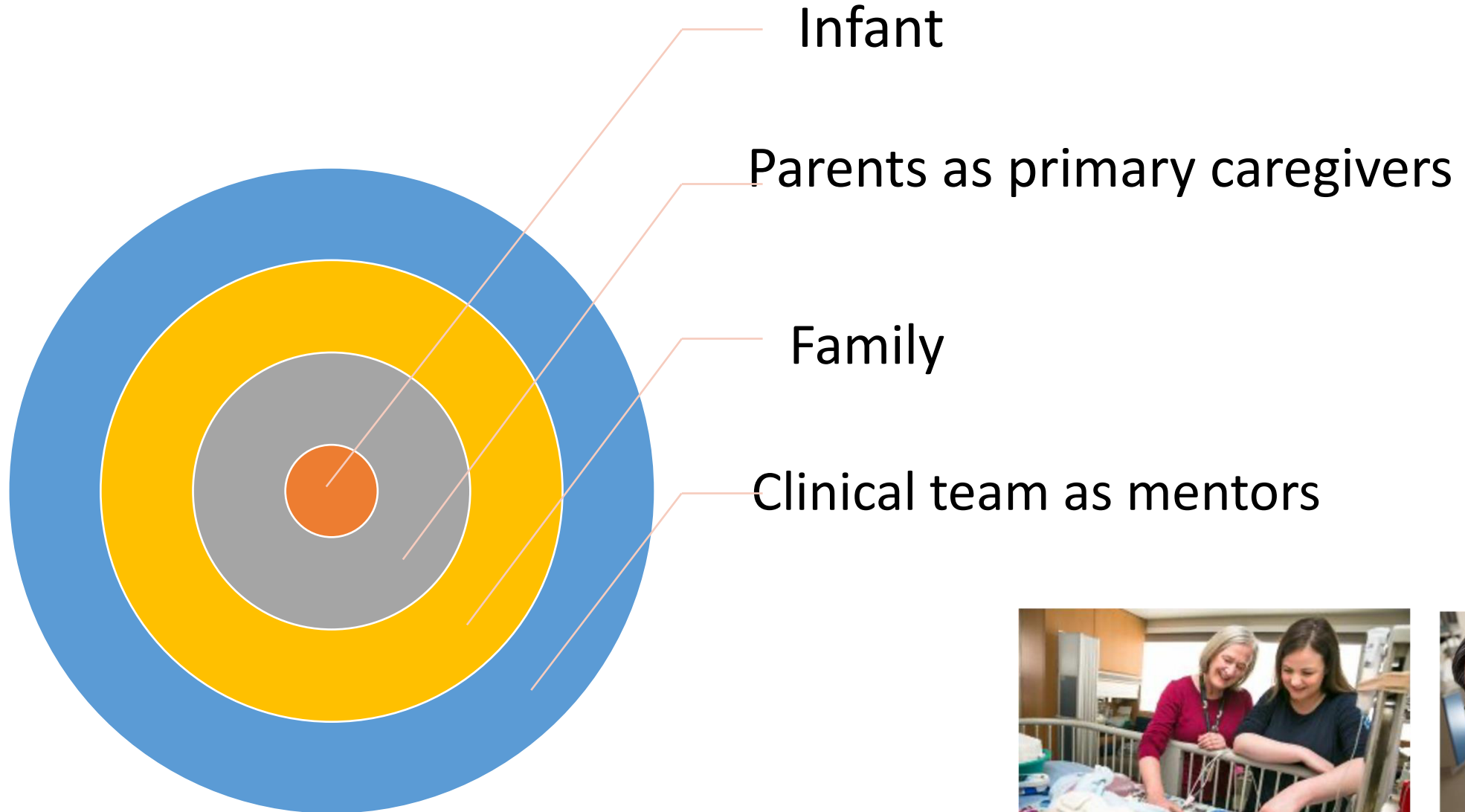
I remain expressionless, listening.









Family Integrated Care: Parents as primary caregivers





Effectiveness of Family Integrated Care in neonatal intensive care units on infant and parent outcomes: a multicentre, multinational, cluster-randomised controlled trial

Karel O'Brien, FRCPC   • [Kate Robson, MEd, E Ng](#) • [Marianne Bracht, RN](#) • [Melinda Cruz, BSc](#) • [Prof Kei Lui, MD](#) • [Ruben Alvaro, MD](#) • et al. [Show all authors](#) • [Show footnotes](#)



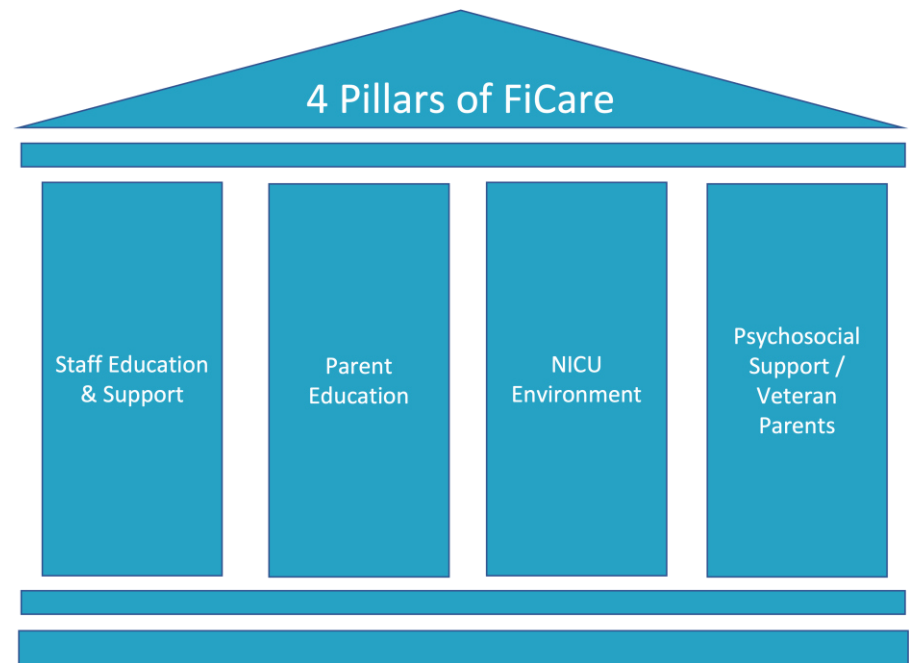
26 NICUs in Canada, Australia and New Zealand

Parental intervention:

- Presence > 6 hours per day
- Attend educational sessions
- Actively involved in infant care

Significant Outcomes:

- Higher daily weight gain
- Higher breast milk feeding at discharge
- Lower parental stress scores





Eight principles for patient-centred and family-centred care for newborns in the neonatal intensive care unit

Jean-Michel Roué,¹ Pierre Kuhn,² Maria Lopez Maestro,³ Ragnhild Agnethe Maastrup,⁴ Delphine Mitanchez,⁵ Björn Westrup,⁶ Jacques Sizun⁷

Table 1 Evidence for the eight principles for family-centred care

No	Standard	Nature of evidence (ref)
1	Free 24 hours/24 parental access	Human approach
2	Psychological parental support	Meta-analysis
3	Pain management	Meta-analysis
4	Environmental influences	Observational studies Meta-analysis
5	Postural support	Meta-analysis
6	Support of skin to skin	Meta-analysis
7	Lactation and breastfeeding support	Meta-analysis
8	Sleep protection	Animal studies







PATIENT'S NAME: <i>Your BARY</i>					
All Routes: As Required Prescriptions					
DRUG <i>Kangaroo Care</i>			STOPPED <small>DATE</small> <small>REASON</small>	DATE	
DOSE <i>1 hold</i>	ROUTE <i>cut</i>	INDICATION <i>EVERY BABY</i>		TIME	
PRESCRIBER SIGN & PRINT <i>A DOCTOR</i>		MAX.FREQUENCY <i>AS REQUIRED</i>	DATE:	DOSE	
				GIVEN BY	
ADDITIONAL INSTRUCTIONS / COMMENTS / PHARMACY					
DRUG <i>Encouragement</i>			STOPPED <small>DATE</small> <small>REASON</small>	DATE	
DOSE <i>Unlimited</i>	ROUTE	INDICATION <i>Self-doubt</i>		TIME	
PRESCRIBER SIGN & PRINT <i>A DOCTOR</i>		MAX.FREQUENCY <i>ALL THE TIME</i>	DATE:	DOSE	
				GIVEN BY	
ADDITIONAL INSTRUCTIONS / COMMENTS / PHARMACY					
DRUG <i>RE ASSURANCE</i>			STOPPED <small>DATE</small> <small>REASON</small>	DATE	
DOSE <i>Plenty</i>	ROUTE <i>AT BEDSIDE</i>	INDICATION <i>QUESTIONING</i>		TIME	
PRESCRIBER SIGN & PRINT <i>A DOCTOR</i>		MAX.FREQUENCY <i>AS REQUIRED</i>	DATE:	DOSE	
				GIVEN BY	
ADDITIONAL INSTRUCTIONS / COMMENTS / PHARMACY					
DRUG <i>KINDNESS</i>			STOPPED <small>DATE</small> <small>REASON</small>	DATE	
DOSE <i>1 CUP</i>	ROUTE <i>HUG</i>	INDICATION <i>DISTRESS</i>		TIME	
PRESCRIBER SIGN & PRINT <i>A DOCTOR</i>		MAX.FREQUENCY <i>UNLIMITED</i>	DATE:	DOSE	
				GIVEN BY	
ADDITIONAL INSTRUCTIONS / COMMENTS / PHARMACY					



Listening



Lexi



I have been a very good girl overnight.
Had a very good sleep and guzzled
all my yummy milk :-> My blood
sugars are getting better.

Can't wait to see you's mummy +
Daddy + get cuddles.

Love Lexi ♡ xx





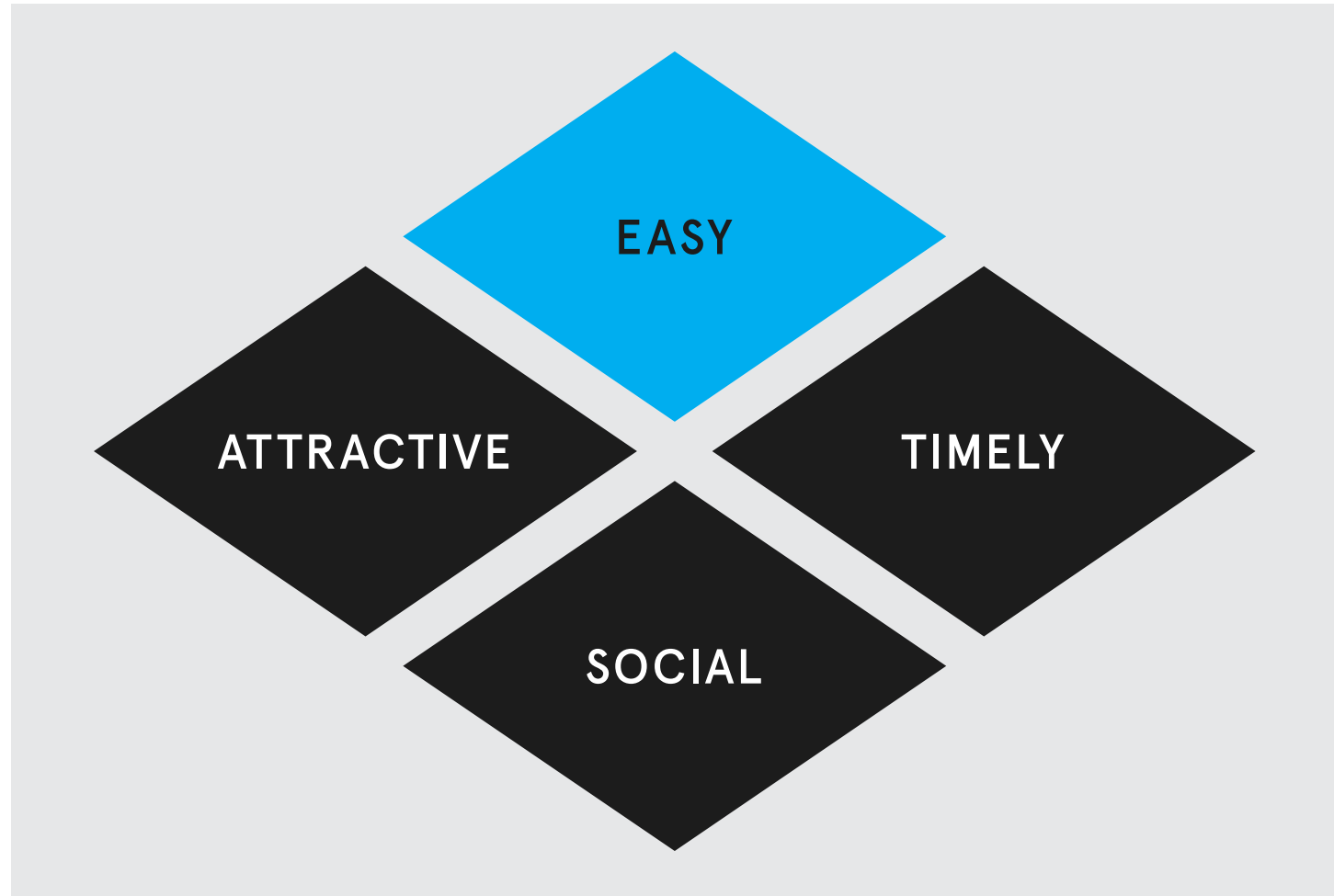




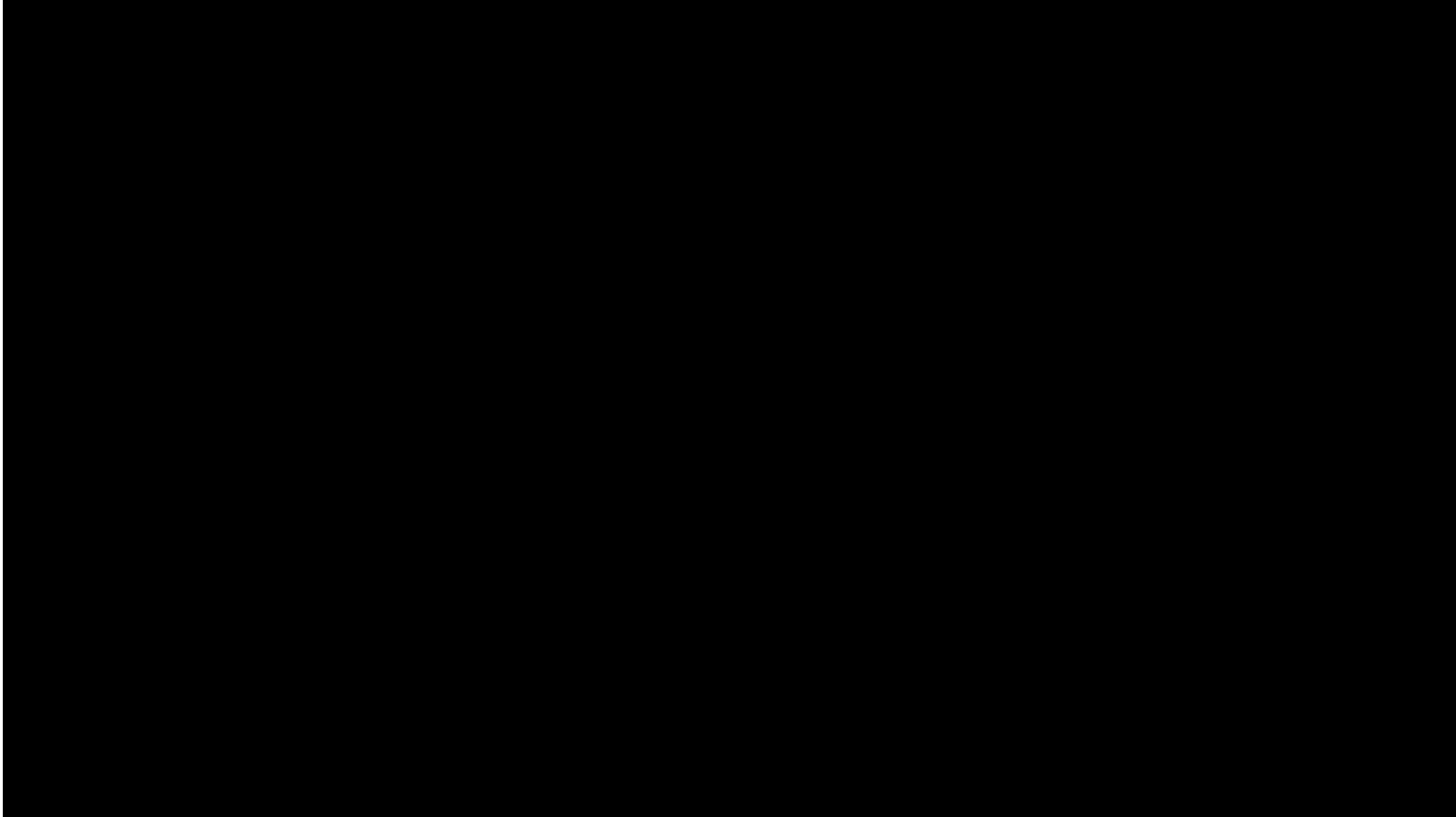


Nudging...

“Enabling people to make better choices for themselves”

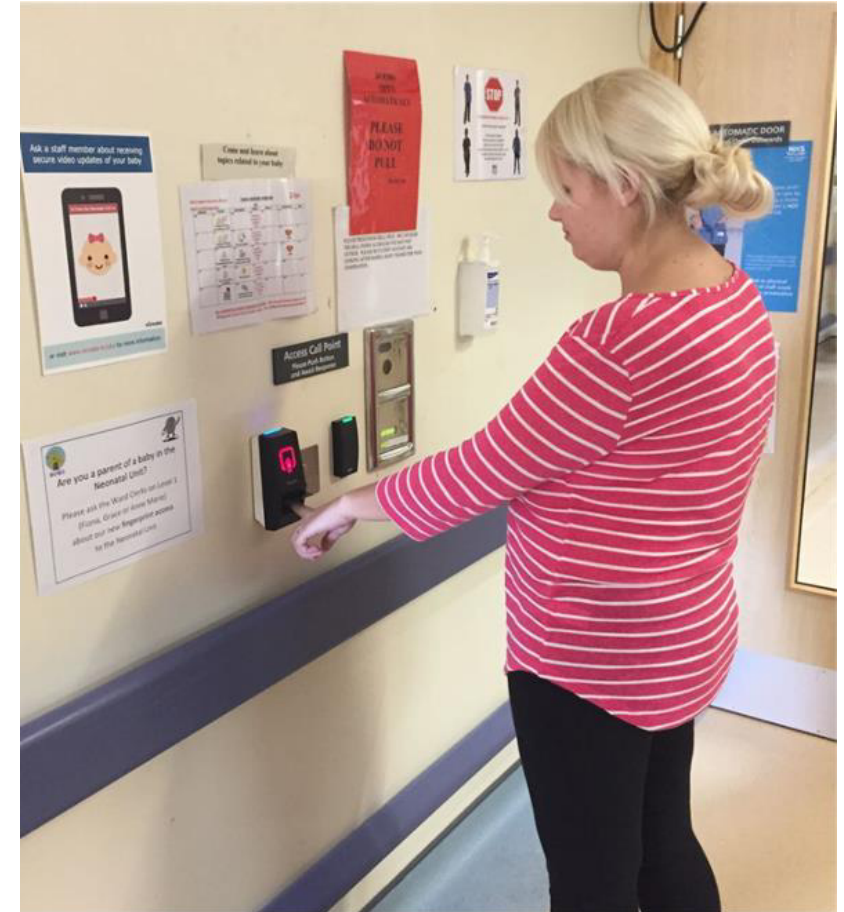


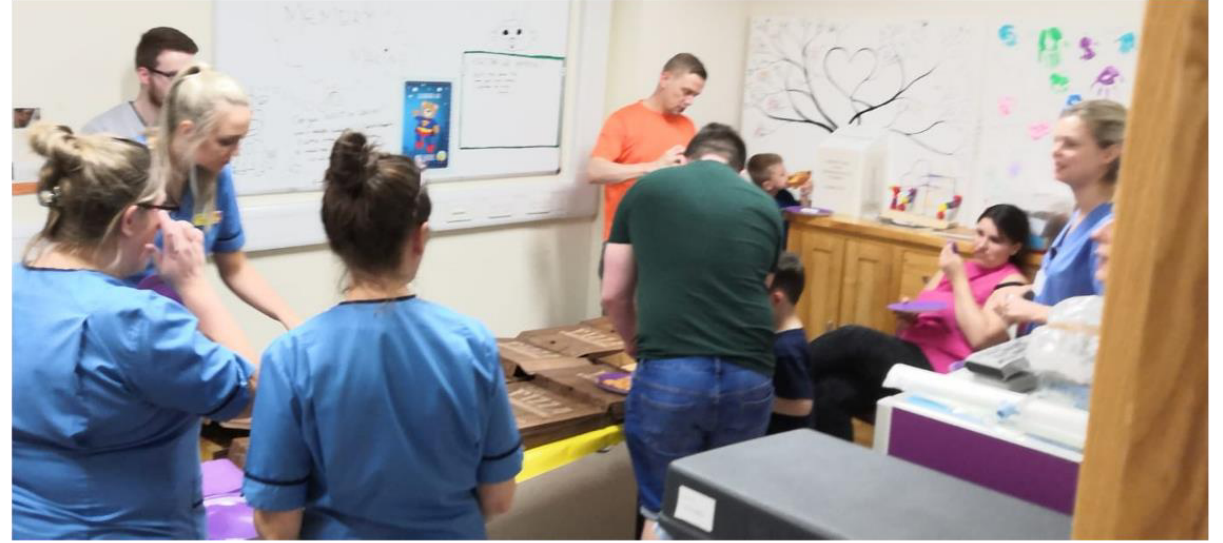
THE
BEHAVIOURAL
INSIGHTS TEAM





A shared "home"









vCreate[®]



Thoughts from a parent in the NICU



Asynchronous video messaging promotes family involvement and mitigates separation in neonatal care

Sandy Kirolos ¹, Lynsey Sutcliffe,² Maria Giatsi Clausen,³ Carolyn Abernethy,¹ Shanthi Shanmugalingam,⁴ Nicole Bauwens,⁵ Judith Orme,⁶ Kirsty Thomson,⁷ Rosemary Grattan,⁷ Neil Patel²

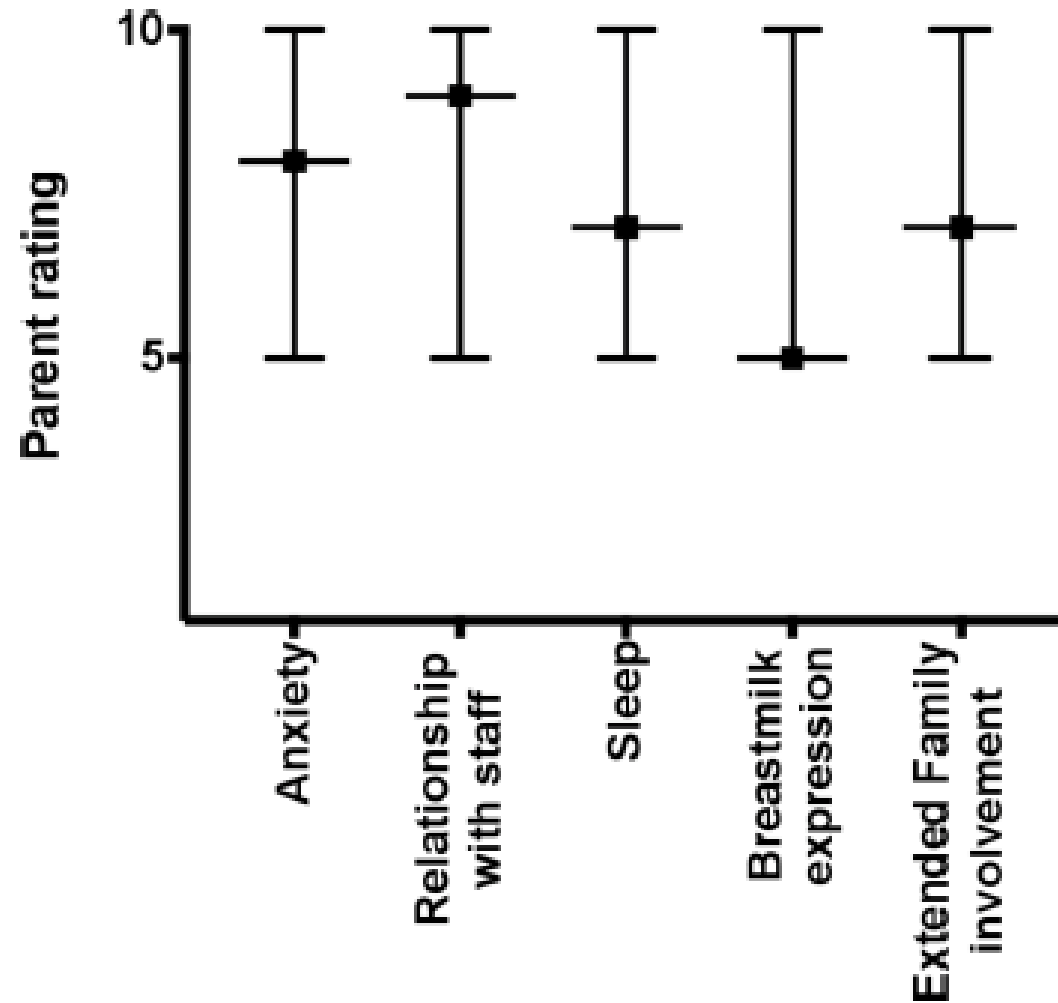



Figure 1 Parent-reported impact of video messages; data presented as median and range. Parent rating: 1=greatest negative impact, 5=no impact, 10=greatest positive impact.

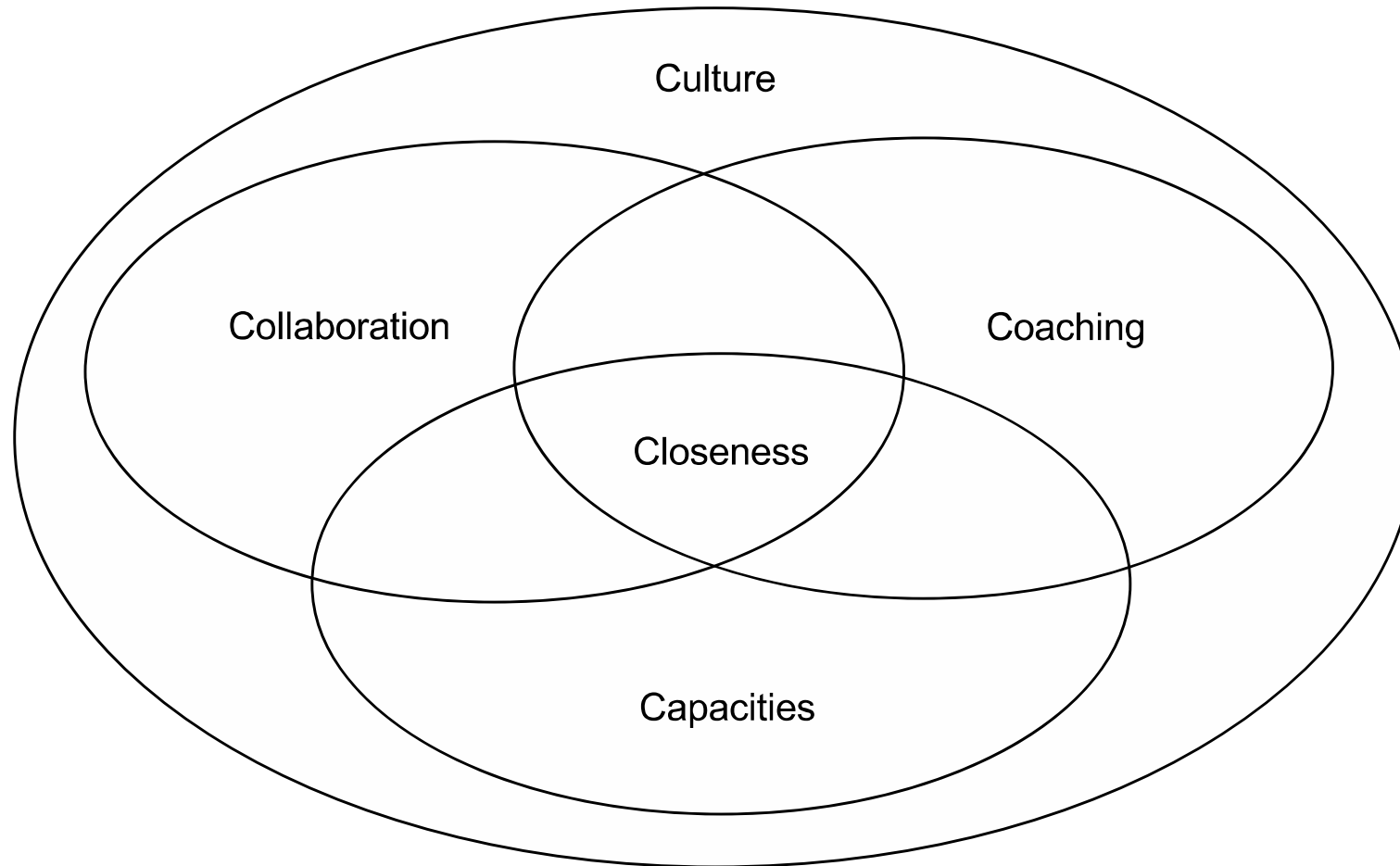




An international study on implementation and facilitators and barriers for parent-infant closeness in neonatal units



Nicole R. van Veenendaal^{1,2}  | Nanon H.M. Labrie^{1,3}  | Silke Mader⁴ | Anne A. M. W. van Kempen¹  |
Sophie R. D. van der Schoor¹  | Johannes B. van Goudoever²  | CROWN Study Group*



External support, collaboration and





Bliss
for babies born
premature or sick

Bliss Baby Charter Gold Accreditation

This accreditation has been awarded to

Royal Hospital for Children, Glasgow

for their continued commitment to the
Bliss Baby Charter standards of family-centred care.

This follows a successful assessment where it was demonstrated that sufficient
processes and facilities are in place for the delivery of high quality family-centred care.

This accreditation is valid for **September 2022 to September 2025**

Registered charity no. 1002973 Scottish registered charity SC040678





The ethics of family integrated care in the NICU: Improving care for families without causing harm

Annie Janvier^{a,b,c,d,e,f,g,h,*}, Michael-Andrew Asaad^{a,b}, Martin Reichherzer^b,
Catherine Cantin^{b,h}, Maia Sureauⁱ, Josée Princeⁱ, Thuy Mai Luu^{a,c}, and
Keith J Barrington^{a,b,c}

*“There are many questions that made me uneasy.
I do not want to feed my baby with a tube.
I never have wanted to describe her at rounds.”*

Personalizing care, offering choice...

My family Profile

My mum & dad are.....

I was born on _____
at _____ hospital
— weeks premature
by _____

Things I like are:
my favorite position is _____
I have a soother Yes/no
Singing Stories

I am fed;
mums milk
mums milk + formula
formula
mum expresses mls day
mum has accessed support to express. Yes/No.
 mum would like support to express. Yes/No.

my mum & dad like to / can / are trained to do;
 change nappy ^{signals before}
 change clothes/wash
 tube feed
 bottle feed
 take temp
 warm milk
 replenish kidneys
 other _____

What matters to me **What matters to my family**

HUGG

I was born on _____
at _____
weighing in at _____
weeks gestation

My family are _____

WHAT DO I LIKE?

PLEASE COULD I HAVE A PERSONALISED VIDEO MESSAGE

SMS I WOULD LIKE TO RECEIVE UPDATE TEXTS

My feeds are

My family can	Un-aided	Help us
Cuddle me	<input type="checkbox"/>	<input type="checkbox"/>
Kangaroo Care	<input type="checkbox"/>	<input type="checkbox"/>
Bathtime	<input type="checkbox"/>	<input type="checkbox"/>
Changing	<input type="checkbox"/>	<input type="checkbox"/>
Getting my milk	<input type="checkbox"/>	<input type="checkbox"/>
Oral Feeds	<input type="checkbox"/>	<input type="checkbox"/>
Tube Feeds	<input type="checkbox"/>	<input type="checkbox"/>
Giving medicine	<input type="checkbox"/>	<input type="checkbox"/>
Extra special cares	<input type="checkbox"/>	<input type="checkbox"/>

Wed like to talk about
Expressing Bottlefeeding

My mum is expressing
_____ mls today

I would like to see the rest of the unit



A national Scottish approach to FICare: 5 foundations



ORIENTATION

ACCESS

PSYCHOLOGY

AHPs

TRANSITION



Photograph, Neil Patel,



Supporting every family





Ethnic minority fathers' experiences of the Neonatal Care Unit: barriers to accessing psychological support



Hibah Hassan^a, Fin Williams^a, Jacinta Cordwell^b and Joanna Mann^b

Table 1. Summary of themes and subthemes.

Theme	Subtheme
1. Psychology is a Threat	1.1. Needing to be Strong 1.2. Incompatible with Masculinity
2. It's Not Really Talked about in our Culture	
3. A Space for Mum, Not Me	

Listening and learning...





*“ we don’t just look after babies,
we look after families...”*



Thank you and join us in Glasgow for the 7th International FICare Conference!



**Glasgow
Children's
Hospital
Charity**

Bliss
for babies born
premature or sick



**Scottish
Book Trust**
inspiring readers and writers

vCreate

7th International Family Integrated Care Conference

Wednesday 2nd – Thursday 3rd October 2024
Hybrid Conference



Marnie.mcveigh@ggc.scot.nhs.uk

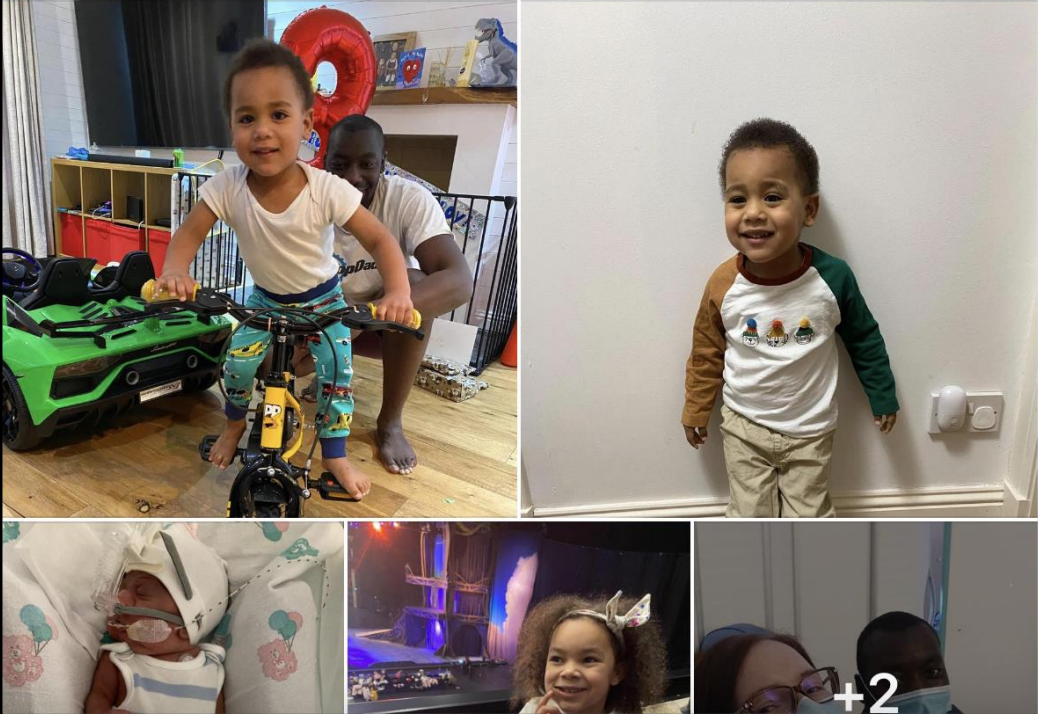
neil.patel@ggc.scot.nhs.uk



Neonatal Unit RHC Glasgow

April 18 at 10:00 AM · 🌐

Look who's not so tiny now 🥰
Superstar Leon celebrated his 3rd birthday last month 🎂
Thank you to his mum Suzanne for this lovely update 🥰
"... See more



Neonatal Unit RHC Glasgow

April 23 at 2:28 PM · 🌐

Superstar neonatal unit graduate Khilan was born with a Congenital diaphragmatic hernia (CDH). She spent three months being cared for in the unit here at the [Royal Hospital for Children, Glasgow](#)
Her family have sent us these fabulous photos of Khilan. 💜 It's lovely to see just how far she's come on at home 🥰
Your looking fabulous Khilan, we love your big bow 🎀
#... See more





Family Integrated Care

A BAPM Framework for Practice


November 2021



British Association of
Perinatal Medicine



Family integrated care: very preterm neurodevelopmental outcomes at 18 months

Anne R Synnes ,^{1,2} Julie Petrie,³ Ruth E Grunau,^{2,4} Paige Church,^{5,6} Edmond Kelly,^{6,7} Diane Moddemann,⁸ Xiang Ye,⁹ Shoo K Lee,^{6,7} Karel O'Brien,^{6,7} Canadian Neonatal Network Investigators, Canadian Neonatal Follow-Up Network Investigators

	Adjusted difference in mean (95% CI) FICare vs Control	
18-month weight (kg)	-0.15 (-0.45 to 0.15)	0.33
18-month BMI	0.67 (0.36 to 0.99)	<0.0001
18-month head circumference (cm)	-0.38 (-0.74 to -0.01)	0.043
Bayley-III language score	0.97 (-2.63 to 4.58)	0.6
Bayley-III cognitive score	1.25 (-1.7 to 4.2)	0.4
Bayley-III motor score	3.87 (1.22 to 6.53)	0.0044



OUR VISION:

“Everyone will **work together** to ensure that **parents are empowered** to be **primary caregivers** with the confidence to care for their **baby** during their stay in the neonatal unit, through their transition to home and beyond.”



The ethics of family integrated care in the NICU: Improving care for families without causing harm

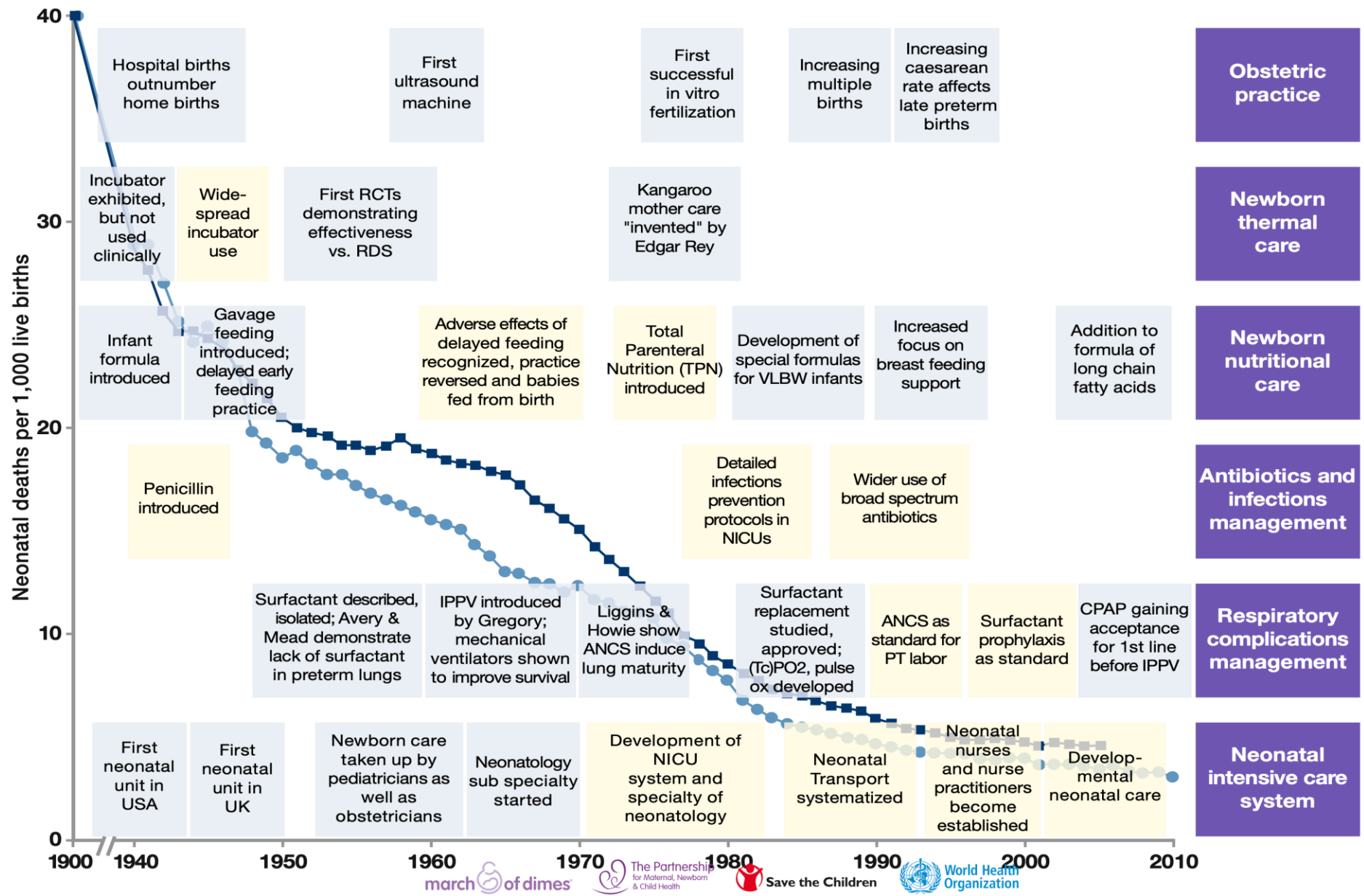
Annie Janvier^{a,b,c,d,e,f,g,h,*}, Michael-Andrew Asaad^{a,b}, Martin Reichherzer^b,
Catherine Cantin^{b,h}, Maia Sureauⁱ, Josée Princeⁱ, Thuy Mai Luu^{a,c}, and
Keith J Barrington^{a,b,c}

*“We have failed our birth, delivery and breastfeeding.
We cannot face more failures. You need to realize you
can crush us with one small comment that was not
meant to hurt us”*



Neonatal mortality rate (deaths under 28 days per 1,000 live births)

—●— England & Wales
 —■— USA
 Innovation/introduction
 Wide-scale use







5 Future Foundations of Scottish FICare



ORIENTATION

ACCESS

PSYCHOLOGY

AHPs

TRANSITION



CHALLENGES/FOR ACCESS. BARRIERS
 MANAGEMENT - SAFETY CONC
 COST - WHO WILL PAY?
 ← FUNDING
 ENDOWMENTS/YEAREND CASH
 SWIPE CARDS - NOT ENOUGH CARDS
 - CARDS NOT RETURNED
 WHO CAN INSTALL?
 DATA CONCERNS.
 POLITICAL ALIGNMENT



PSYCHOLOGY
 EQUITY OF PROVISION
 MONEY - COST
 - FOLLOW UP.
 - LANGUAGE BARRIERS.
 - COMMUNICATION - TRAINING -
 - RESOURCES - SIGNPOSTING FOR ALL
 - ACCESS TO RESOURCES.
 - TRAUMA INFORMED.
 - NETWORKING / COLLABORA
 - NATIONAL FORUM -

AHP
 (CORE COMPONENT OF UNIT
 "CORE BUSINESS" → Support & recommendation, NATIONAL FUNDING
 FUNDING - Not dedicated to neonatal units
 - 75% under-funded (of 7.7m)
 LIMITED ACCESS - Time limited.
 APPRECIATION OF ROLE + IMPORTANCE OF COOPERATION
 "Developmental Therapist" / "HARD" roles
 INFORMATION ABOUT ROLE →
 RISK of not having - delayed diag. etc
 - Use of Risk Register
 FAMILIES / "Patient" voice - LIVED EXPERIENCE
 POLITICAL PRESSURE / SUPPORT.
 SAFETY Relevant → OATIX?
 EARLY Intervention important
 PARENT SURVEY → on duty

TRANSITION
 WHAT DO WE NEED?
 - PARENT PASSPORT - INFO BETWEEN UNITS
 - LINK BETWEEN RESOURCES.
 - ORIENTATION TO OUTSIDE AMMENITIES. LOCALLY
 - CHAT FOR REPAT ♡
 - SHARED EXPERIENCE FROM GRADUATE PARENTS
 WHAT CAN WE DO BETTER?
 - LOOKING AT INFO AVAILABLE.
 MATTERS TO ME.
 CONNECTION TO OTHER SERVICES
 INVOLVEMENT WITH PARENT, other units
 in - Information



Parents' Experiences of Communication in Neonatal Care (PEC): a neonatal survey refined for real-time parent feedback

Susanna Sakonidou ,¹ Sophia Kotzamanis,¹ Amy Tallett,² Alan J Poots,² Neena Modi ,¹ Derek Bell,³ Chris Gale ¹

Development and validation of Neonatal Satisfaction Survey – NSS-13

Inger H. Hagen MHS, RN (Assistant Professor)^{1,2}, Tove B. Vadset MHS, RN (Assistant Professor)^{1,2}, Johan Barstad MSc (Research Manager)³ and Marit F. Svindseth PhD, MHS, RN (Associate Professor)¹

¹Aalesund University College, Aalesund, Norway, ²Department of Pediatrics, Møre and Romsdal Hospital Trust, Aalesund Hospital, Aalesund, Norway and ³Møre and Romsdal Hospital Trust, Aalesund, Norway

Development and validation of a neonatal intensive care parent satisfaction instrument*

Latour, Jos M. RN, PhD, FEFCCNa; Duivenvoorden, Hugo J. PhD; Hazelzet, Jan A. MD, PhD, FCCM; van Goudoever, Johannes B. MD, PhD

[Author Information](#) 

Pediatric Critical Care Medicine 13(5):p 554-559, September 2012. | DOI: 10.1097/PCC.0b013e318238b80a