



Care centred on families: evidence and implementation

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Neonatologist

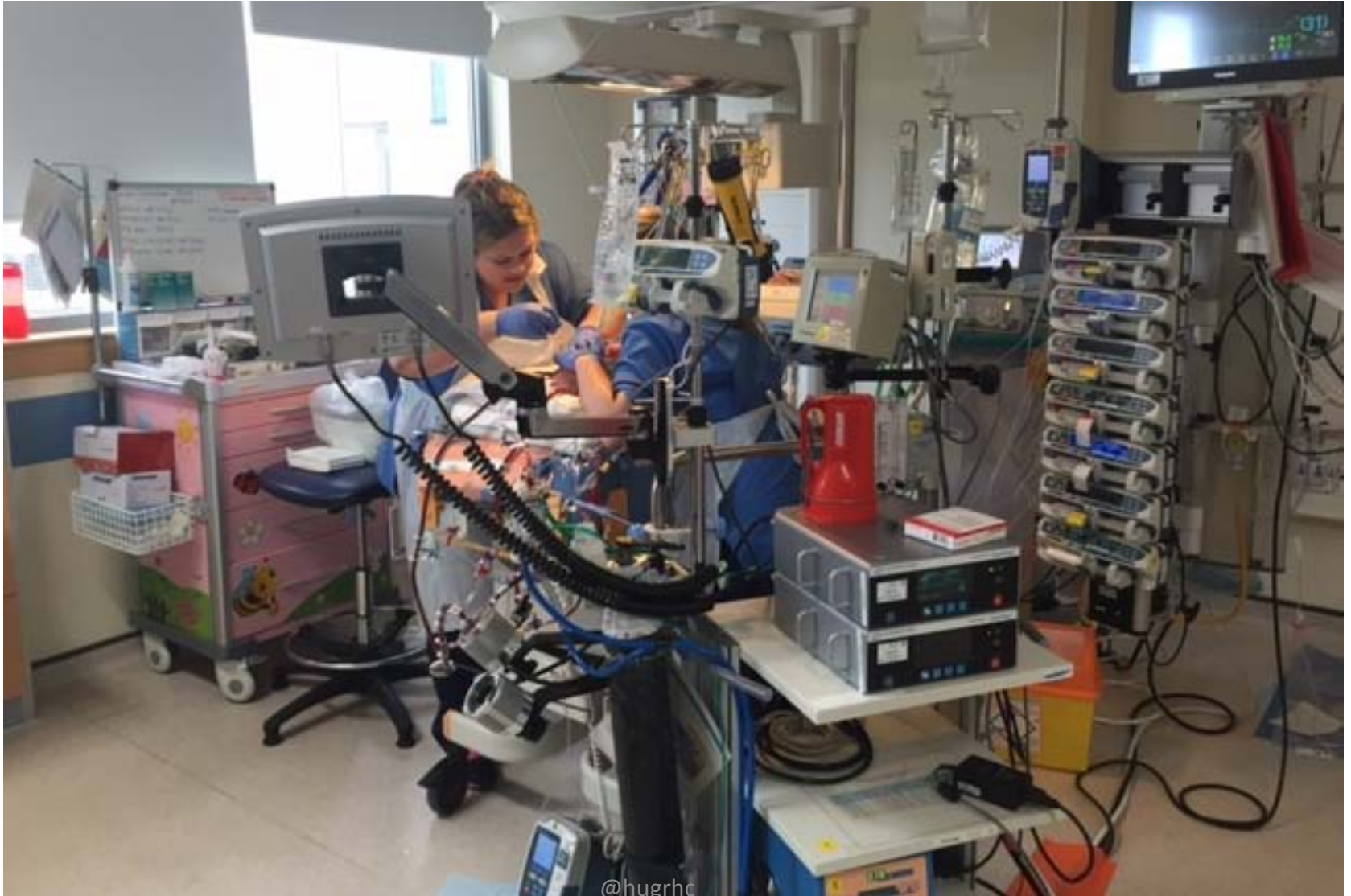
On behalf of the “Helping Us Grow” Group

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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



A pilot cohort analytic study of Family Integrated Care in a Canadian neonatal intensive care unit

Karel O'Brien^{1,2*}, Marianne Bracht², Kristy Macdonell², Tammy McBride², Kate Robson², Lori O'Leary², Kristen Christie², Mary Galarza², Tenzin Dicky², Adik Levin³, Shoo K Lee^{2,4}

Subjects: 42 primary caregivers and their infants, < 35weeks gestation

Intervention:

- Caregivers attended > 8 hours per day
- Daily parent education sessions
- Mentoring by bedside nurses

Outcomes:

- Significant increase in rate of change of weight gain
- Increased breast-feeding rates
- Decreased Parental Stress Survey score



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

	FiCare (n=895)	Standard Care (n=891)	P
Average daily weight gain	26.7 (9.4)	24.8 (9.5)	<0.0001
Exclusive breastmilk feeding at discharge	70%	63%	0.016
Parental stress score	2.3 (0.8)	2.5 (0.8)	P<0.0004

O'Brien et al, Lancet Child and Adolescent Health, 2018



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PATIENT'S NAME: <i>Your BARY</i>							
All Routes: As Required Prescriptions							
DRUG <i>Kangaroo Cafe</i>			STOPPED <small>DATE</small>	DATE			
DOSE <i>1 hold</i>	ROUTE <i>cut</i>	INDICATOR <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>	DATE			
DOSE <i>Unlimited</i>	ROUTE	INDICATOR <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>	DATE			
DOSE <i>Plenty</i>	ROUTE <i>AT BEDSIDE</i>	INDICATOR <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>	DATE			
DOSE <i>1 CUP</i>	ROUTE <i>HUG</i>	INDICATOR <i>DISTRESS</i>		TIME			
PRESCRIBER SIGN & PRINT <i>A DOCTOR</i>		MAX/FREQUENCY <i>UNLIMITED</i>	DATE:	DOSE			
				GIVEN BY			
ADDITIONAL INSTRUCTIONS / COMMENTS / PHARMACY							

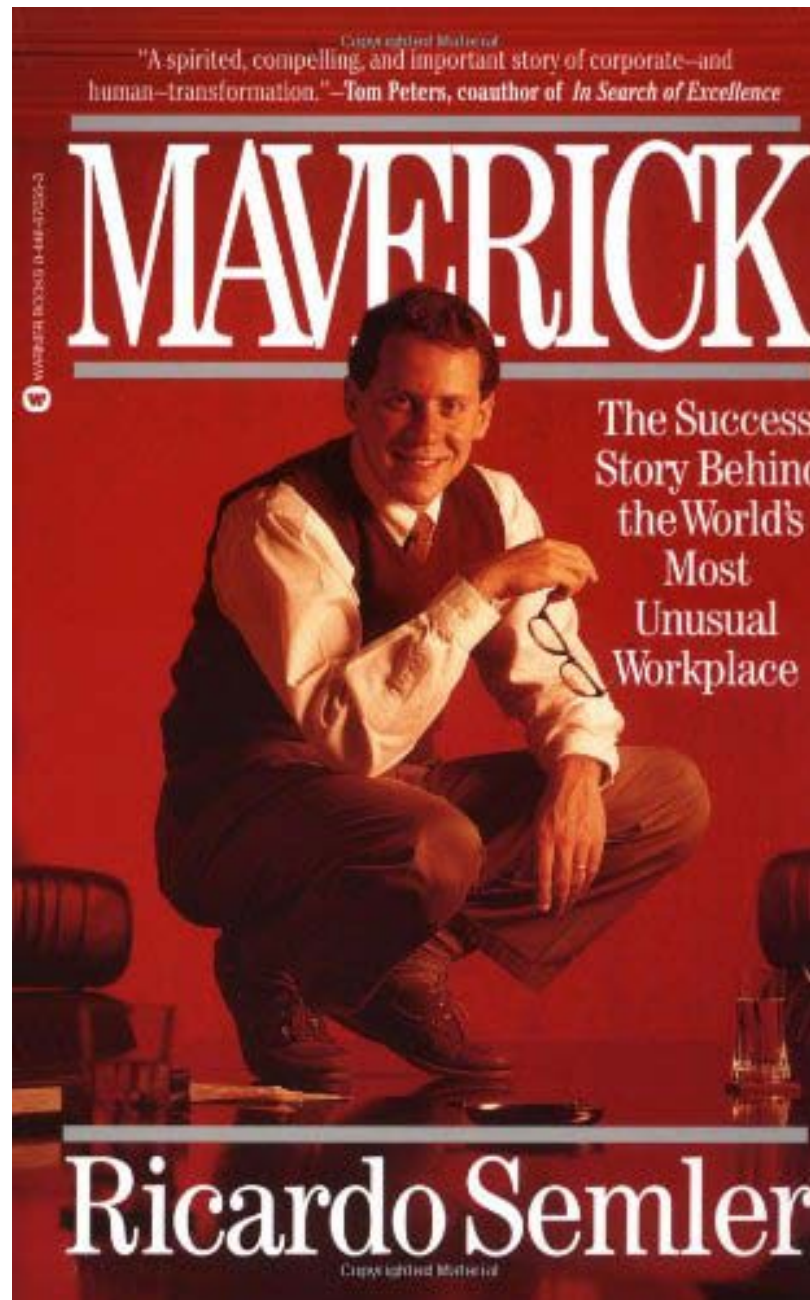




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John Timpson





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LISTENING





Parent feedback: 3 key themes

Wanting to be involved in care:

“It really affects your emotions.....when I can get him out and hold him is a really good day”

“We are here all day.....we want to do everything we can”

Consistency:

“It depends who is on how much you get to do”

“the rules were different on different days”

Education, support and training:

“you don’t know how much you are allowed to do”

“We want to be trained by now”



“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.”



FAMILY EDUCATION

Support parenting in the NNU
Engage parents in care

STAFF EDUCATION

Empower staff to support parents
Ensure consistency of approach

Supporting families in NNU

PEER to PEER

Enable parents to share experiences and support each other

ENVIRONMENT & RESOURCES

Physical factors to support family care

COMMUNICATION

Share our ideas and plans
Improve communication









Thursday 12th
May

Nurses - Janie + Wendy



Dear Janie & Wendy,

Thank you for being my 'voice' for these past days. My communication with mummy and daddy through you has been very precious to them. And also, thank you for taking such a good care of me.

Love,



My family Profile


My mum & dad are.....

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

Things I like are:
 My favourite position is _____
 I have a soother Yes/no
 Singing Stomachs

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;
 change nappies ^{signs before}
 change clothes/wash
 tube feed
 bottle feed
 take temp
 warm milk
 replenish stocks
 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 

I WOULD LIKE TO RECEIVE UPDATE TEXTS 

My feeds are _____

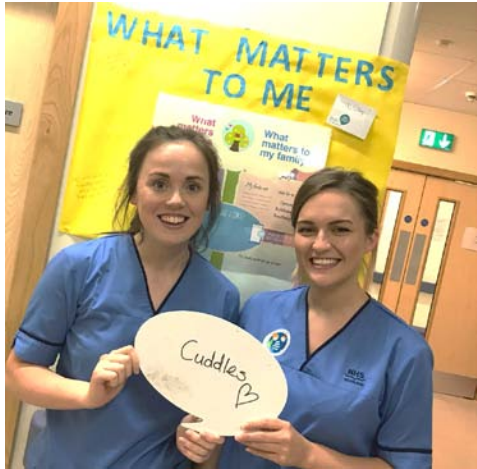
My family can

	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"/>

Expressing Bottlefeeding

My mum is expressing _____ mls today

I would like to see the rest of the unit



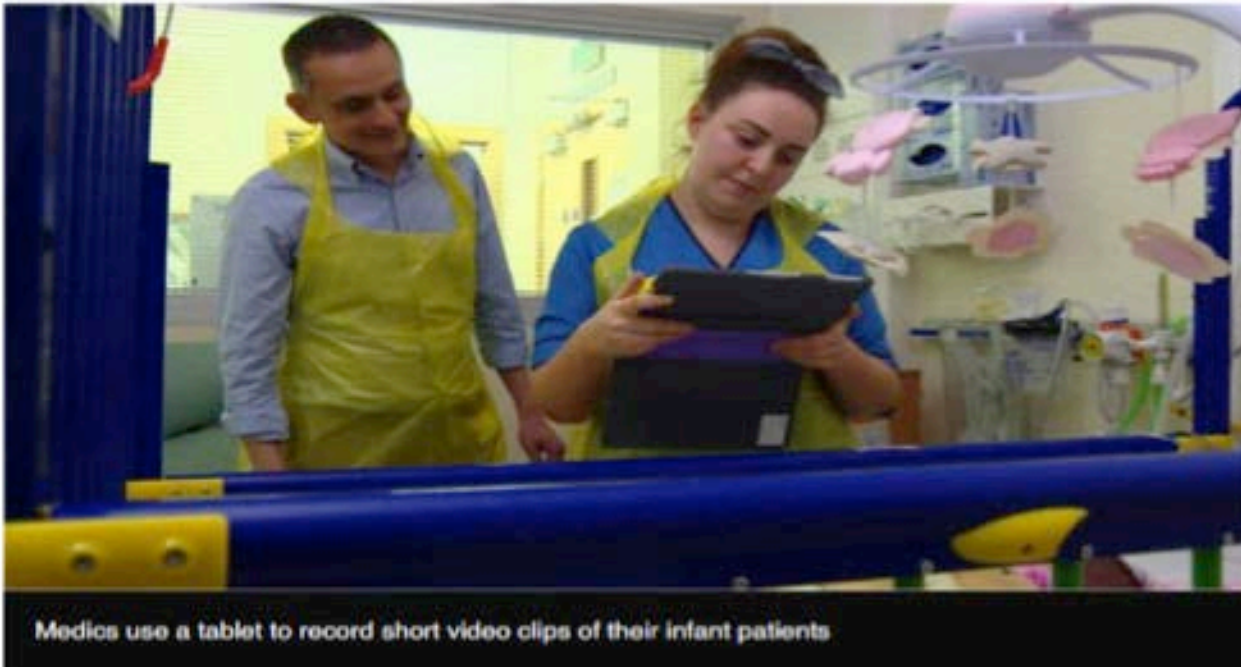


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Medics use video to help parents of neonatal babies





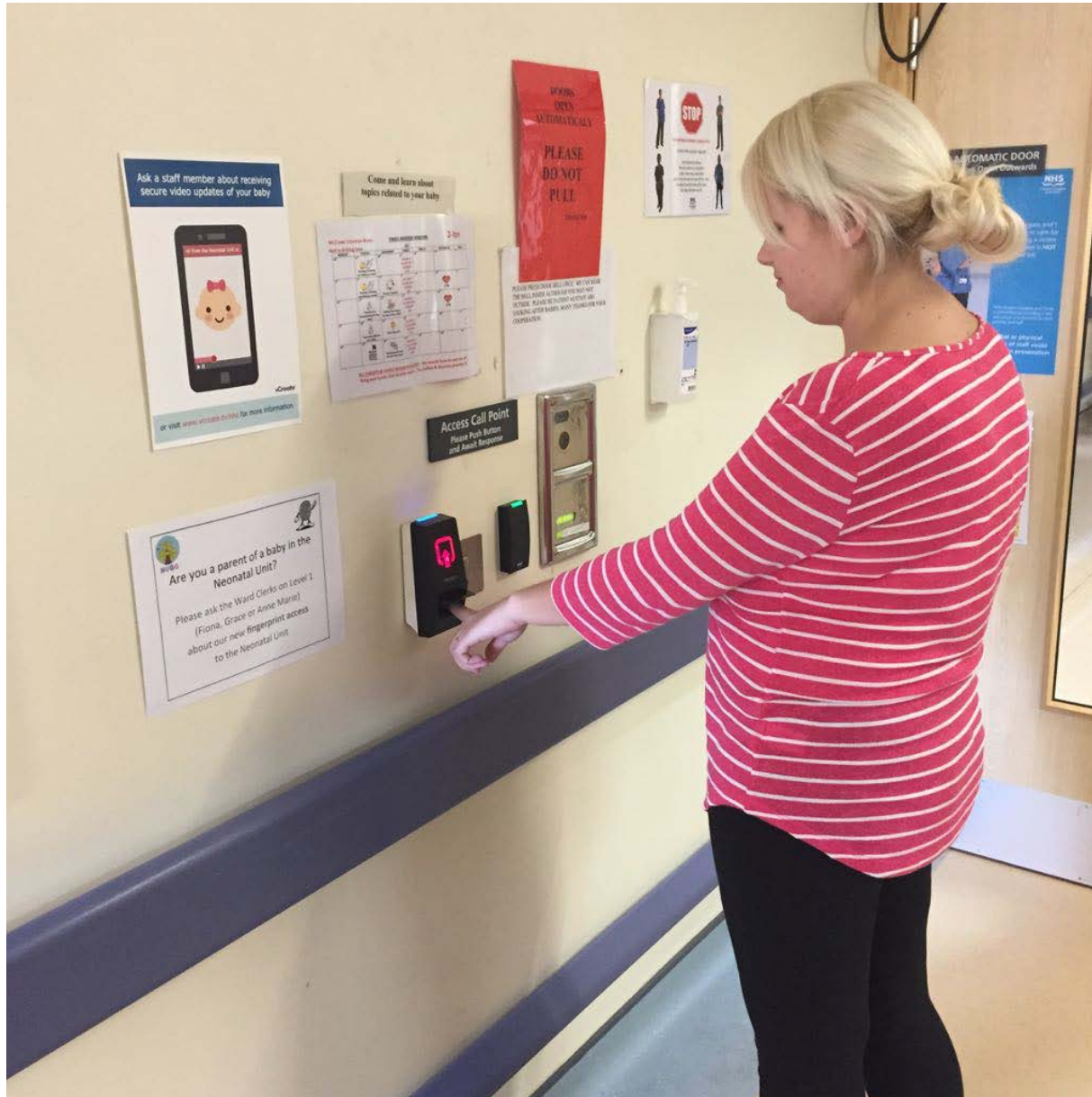


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Thoughts from a parent in the NICU

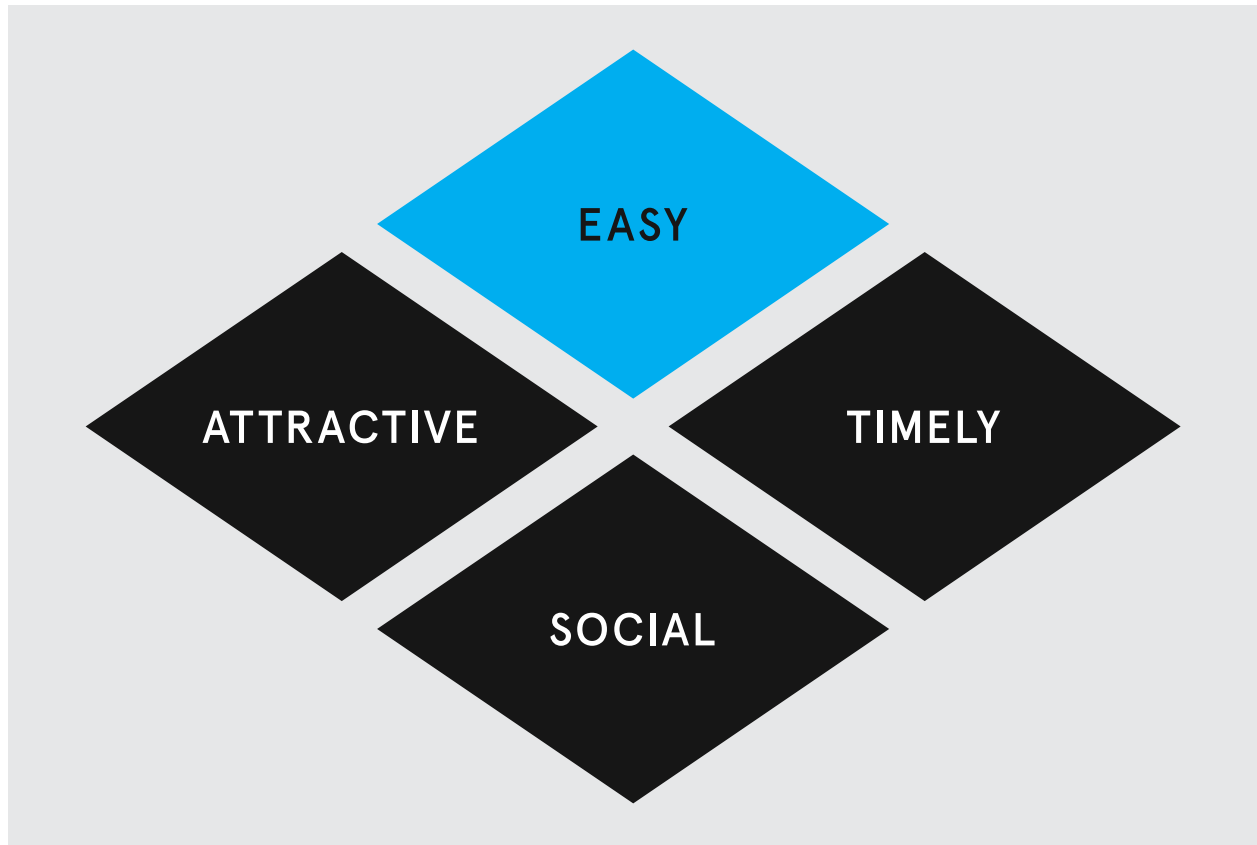








“Enabling people to make better choices for themselves”



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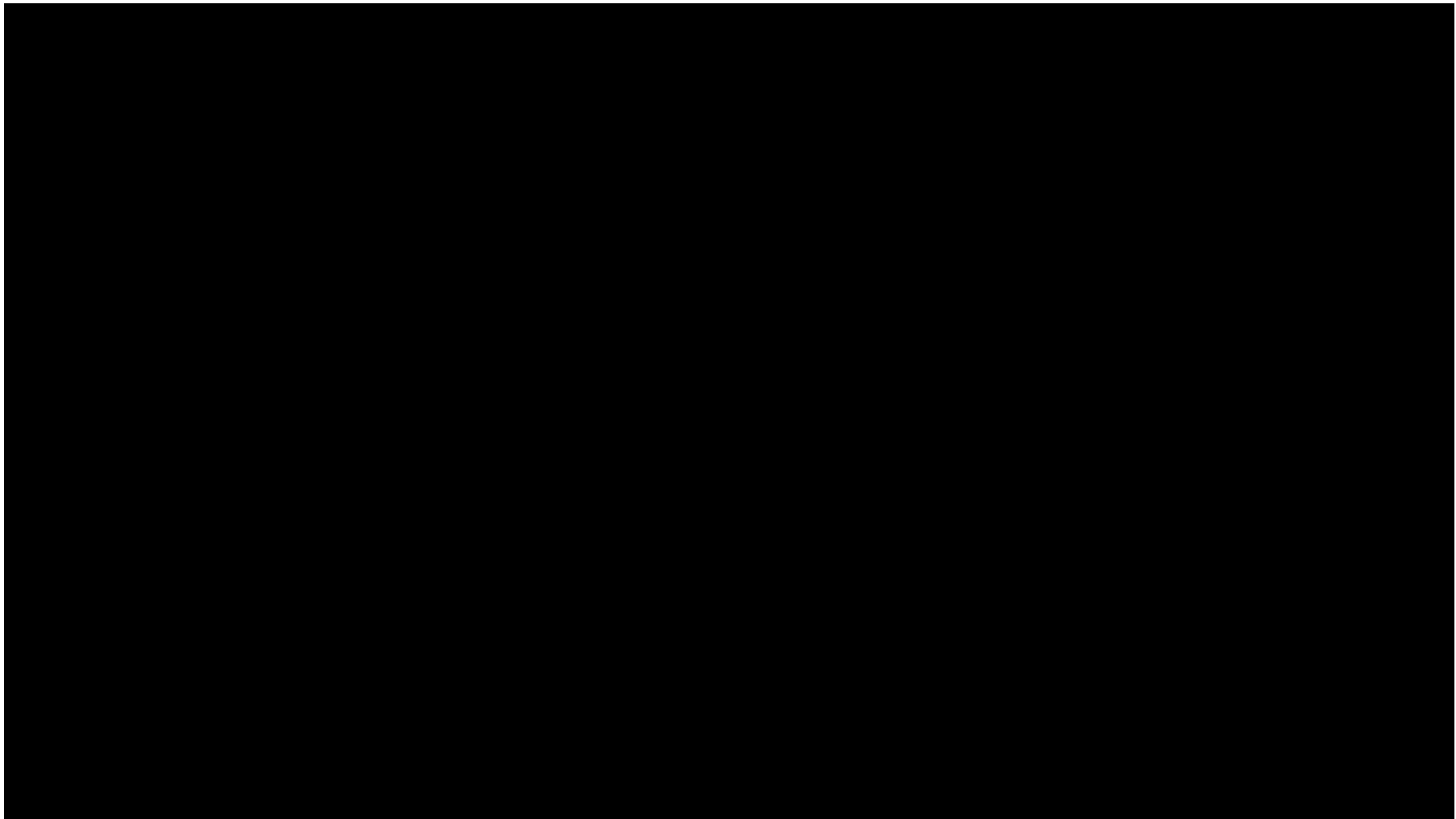


2016: Staff Survey

Do you feel confident supporting parents to give their baby skin to skin care (kangaroo care)?

Yes: 33%

No: 67%





KANGATHON

MAY 1 ST	
MAY 2 ND	
MAY 3 RD	
MAY 4 TH	
MAY 5 TH	
MAY 6 TH	
MAY 7 TH	
MAY 8 TH	
MAY 9 TH	
MAY 10 TH	
MAY 11 TH	
MAY 12 TH	
MAY 13 TH	
MAY 14 TH	
MAY 15 TH	





Neonatal Mental Health Awareness Week 15-21 April 2019



NEONATAL MENTAL
HEALTH AWARENESS
WEEK

#bekindtoyourself

You are the most important person in your baby's life. Your baby needs you to look after yourself emotionally and physically so you can look after him/her.

Clinical Psychology (Maternity & Neonatology) Service, QEUH

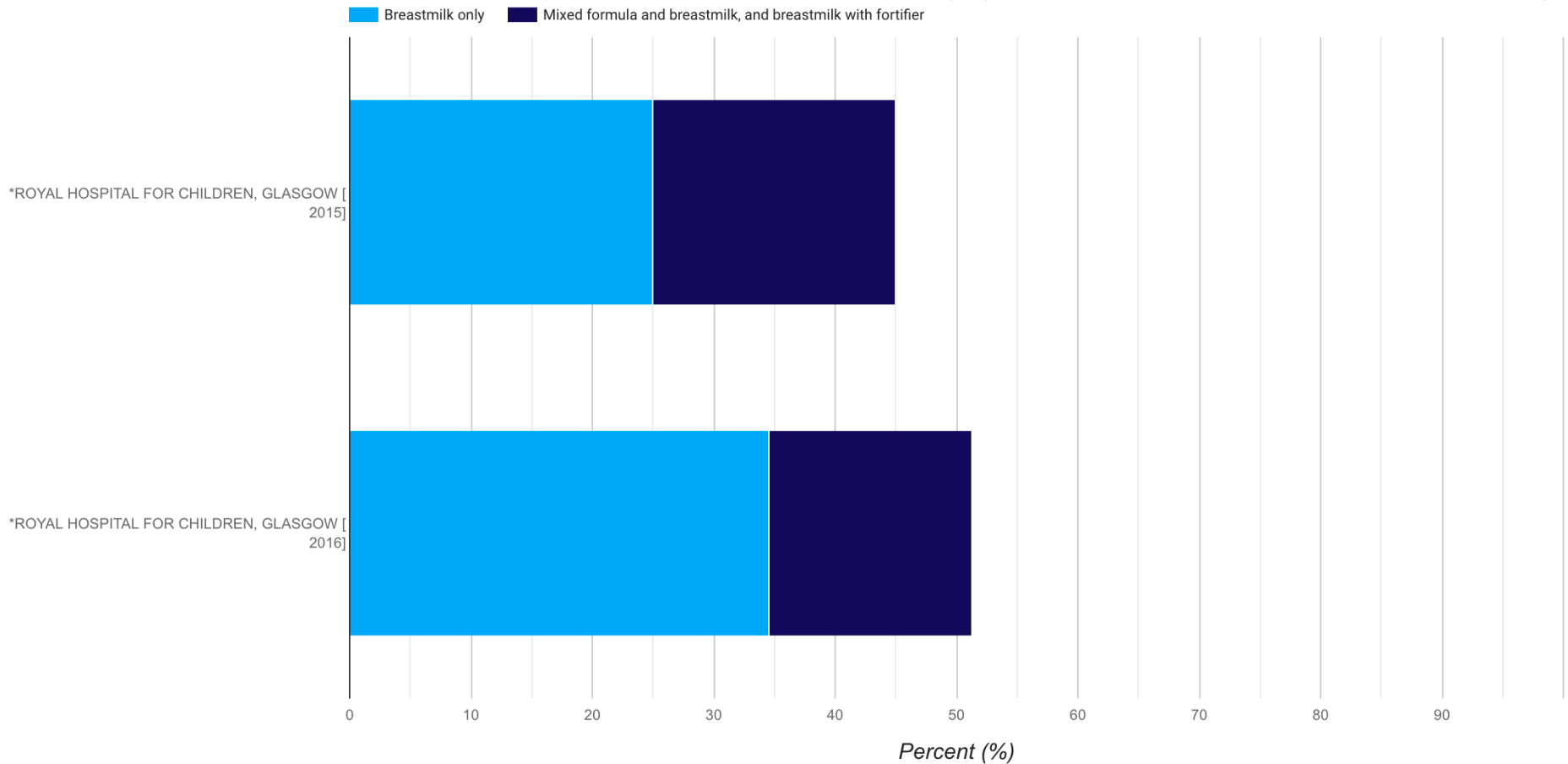


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Proportion of babies receiving Mother's breastmilk at discharge (National Neonatal Audit Data)





Q: Overall do you feel involved in your baby's care?



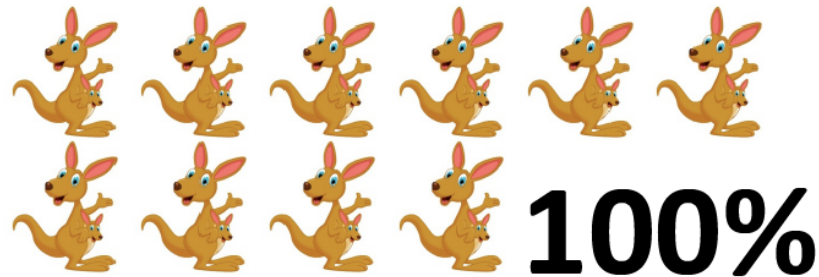
July	August	September	October	November	December	January
60%	100%	75%	71%	95%	88%	100%

Q: Staff understand what matters to me and my baby?



July	August	September	October	November	December	January
100%	100%	100%	100%	100%	88%	100%

Q: Have you or will you hold your baby today?



July	August	September	October	November	December	January
69%	100%	100%	86%	89%	100%	100%



she was 9lb 6oz among much teenier wee pals. I was scared to get to know her but with support I managed to breastfeed her through all the wires and this connection was vital for me. I eventually also managed to make up a silly wee song to sing to her too. Her Dad was good at talking to, changing and holding her. It's whatever works for you, whatever gives that connection.

I felt like I was part of a family. The nurses were there to offer support, met with a friendly smile from when I went in everyday, they always came to me to update me rather than me having to ask. This made me feel supported and therefore able to concentrate on looking after Emin without having any worries. I didn't really appreciate it until now when I sit a reflect about our time spent there.



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ADC Online First, published on November 9, 2017 as 10.1136/archdischild-2017-313282

Leading article



Family Integrated Care: changing the culture in the neonatal unit

Neil Patel, Ainsley Ballantyne, Gillian Bowker, Jack Weightman, Sarah Weightman, for the Helping Us Grow Group (HUGG)

as a "top-down" initiative. Instead, our approach was 'ground up', engaging staff and families in all stages of planning and implementation.^{12, 21} Three key principles guided our work: listening to parents and staff, empowering them to lead change and applying innovation.

Listening to families and staff



NHS SCOTLAND

PRACTISING REALISTIC MEDICINE

 CHANGE OUR STYLE TO SHARED DECISION MAKING?	 BUILD A PERSONALISED APPROACH TO CARE?
 REDUCE HARM AND WASTE?	 REDUCE UNWARRANTED VARIATION IN PRACTICE AND OUTCOMES?
 MANAGE RISK BETTER?	 BECOME IMPROVERS AND INNOVATORS?

Chief Medical Officer's Annual Report 2016-17




HELPING US GROW GROUP (HUGG), ROYAL HOSPITAL FOR CHILDREN, GLASGOW

The Helping Us Grow Group (HUGG) is a unique inclusive collaboration of families and staff in the neonatal unit. Our aims to support parents to be primary caregivers for their baby, no matter how sick, in partnership with clinical staff. This is our model of Family Integrated Care (FIC). Two key elements of our work are education for families and encourage peer-to-peer support.

Inspired by other leading FIC centres, and motivated by feedback from families in our unit, we organised a programme of innovative daily Family Awareness Sessions (Figure 4). These are held most days from 2-3pm for all families in the neonatal unit and aim to give parents skills and knowledge to care for their baby, as well as an important to meet and support each other. Topics are requested by parents and sessions are led by staff of all backgrounds including staff nurses, nursery nurses, neonatal doctors, pharmacists, dietitians and psychologists. "Visitor" parents, both mothers and fathers, also return to lead sessions and share their experiences.

In order to foster collaboration we also developed a simple but effective innovation, shared whiteboards at each cot space. Families are able to leave messages for staff, including when they can be present to care, which care they want to be involved in and their baby's likes and dislikes. Staff especially those on night shifts, write updates and messages of support, including testimonials for non-english speaking families. Parents are added to know that staff are listening. These simple whiteboards have created a new relationship with staff at our neonatal ward "thank you for being a voice for my baby".

Another innovation was inspired by a father in the neonatal unit. He told us that he used video messaging to his clients, and asked if we could send him a video of his baby, working with an industry partner. IT and governance teams we designed and piloted a secure video-messaging system in the neonatal unit in March 2017. Staff create short, friendly video updates for parents when they cannot be with their baby (Figure 5).

Figure 4 HUGG Family Awareness Session



Figure 5 HUGG Video Messaging



The positive impact of this innovation has far exceeded all of our expectations. Parents tell us they feel reassured, less anxious and sleep better. They feel a deeper trust and connect to staff who took the time to make and send the video message of their baby. With the support of grateful families we are now expanding our system to our 60 neonatal units throughout the UK, and to other critical care areas in our organisation.

www.create.tv/secure-video-messaging



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Family Integrated Care: changing the culture in the neonatal unit. Archives of Disease in Childhood 2017.

www.vcreate.tv

<https://player.vcreate.tv/royalhospitalforchildren/kmc2018>

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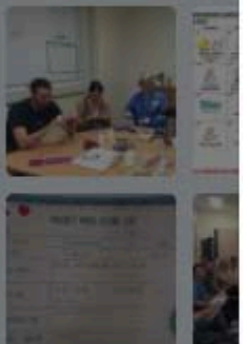
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HUGG- helping us RHC NICU Glasgo and parents to em for their baby in ci circimstances

Glasgow, Scot

Joined May 20

40 Photos and



@HUGGrhc Neil getting a lesson on how to knit xx



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