

# **Minutes of Parents Advisory Group**

# Thursday 05 September 2024 11:00pm – 12:30pm

# **Via Microsoft Teams**

## **Present:**

Cara Hobby (CMH), Deputy Lead Nurse, EMNODN (Chair)

Harriet Leyland (HL), Care Coordinator, EMNODN

Amanda Pike (AP), Parent & Families Engagement Lead, EMNODN

Anita D'Urso (AD), Psychologist, EMNODN

Nicola Hay (NH), Parent Representative, Nottingham

Matt Rutter (MR), Parent Representative, NGH, RDH & QHB

Ellen Cutler (EC), Matron, Nottingham University Hospitals

Julie Versteeg (JV), Family Care Sister, Nottingham University Hospitals (joined at 11:34)

Maisie Partridge, Family Care Sister, Nottingham University Hospitals

Clare Harris (CH), Independent Neonatal Parent Voice Lead, Nott & Notts MNVP

Nafeesah Tutla (NT), Neonatal Co-Lead, LLR MNVP

Michelle Hardwick (MH), Matron, Northampton General Hospital (joined at 11:22)

Nicola Malazzab (NM), FiCare Lead & Governance Lead Nurse, Northampton General Hospital

Sally-Ann Simpson (SAS), Lead FAB Worker, United Lincolnshire Hospitals

Reo Roberts (RR), Trainee ANNP, United Lincolnshire Hospitals (joined at 11:13)

## In Attendance:

Linsay Hill (LSH), Office Manager, EMNODN (Minutes) Laura Delaney (AD), Assistant Clinical Psychologist, EMNODN

	Subject	Attachment	Action
1.	Apologies for Absence Linda Hunn, Jane Lafferty, Louise Wardle, Beth Cooke, Mishal Joshi		
2.	Minutes from the Previous Meeting		
	The minutes were passed as a true record of proceedings.	<u>A</u>	
3.	Matters/Actions Arising The parent who had previously expressed interest is no longer interested but MH has put out a copy of the JD.		
	MR hasn't heard anything since the last meeting regarding the Amazon wish list etc.		
	CH to put Leicester unit managers in touch with NT. NT updated that this wasn't specifically a mental health support group, more just feedback, support etc. Parent feedback has		

been that once discharged there is no psychological support. AD explained from a national perspective there needs to be parallel planning from psychology support when going home. It would be helpful for this to be fed back at LMNS/ICB level. NT is hopeful of being invited to the relevant Board and will be raising this issue with them. SAS comes across this regularly in Lincolnshire, families keen to get home and they then realise that the support network they had on the ward has gone which makes them feel isolated. Part of the FaB role in Lincolnshire is to signpost families. Was there anyone NT was hoping that CMH was hoping to be put in touch with. Not at the moment no but will get in touch if there is anyone else. NH to send photos of the display boards to HL. NH still to do. NH Posters relating to neonatal areas. CMH to resend the West СМН Midlands poster to CH. If anyone else has any posters that give an introduction to neonatal services within antenatal **ALL** areas please also share with CH; clare.harris21@nhs.net. NT also requested any posters to be sent to her too. Free parent car parking in Leicester is progressing and just now awaiting official confirmation. Facebook pages and problems units have had with. CH was going to share LMNS socials information with NH. Have shared the NUH Teddy's Bears picnic information on their socials. Have also now created a TicTok account: nottsmnvp **Update on HIEM Project** One more video still to come back with final edits, it is hoped that these once completed will be a great resource. To provide a brief update; these are 4 educational videos for families around early maternal breastmilk, skin to skin, introduction to FiCare and introduction to Neonatal Operational Delivery Networks. Filming for each of the 360 tours is complete with HL currently working on initial edits. These will then be shared with local teams for further edits/comments. These videos will be helpful in supporting parents before they are moved/transferred.

5.

# 6. Local Parent Feedback ULHT

SAS lots of positive feedback. Maternity hubs have put together lots of resources in the form of borrow bags, treasure baskets, sensory equipment – getting really positive feedback on this!

Lovely feedback on VIG programme – video of shots micro analysed, looking for subtle cues, things that they wouldn't usually see themselves, get to keep the videos. CMH maybe invite to share more information on this at another of our Network meetings.

MR partner suffers with anxiety and VIG really helped.

## SFH

CH – KMH and NUH have full time engagement worker and an engagement lead 3 days per week at SFH. From conversations, generally feedback is positive, one thing that has popped up is around communication, from doctors and consultants, specifically around plans for discharge. Had one Family who had twins at City, a decision was made during the night to move the twins for capacity, from mums perspective the communication really badly handled.

CMH great to hear about the new engagement leads, and would be good for them to link in with AP. CH to share their details with AP. CH will bring Tara and Emma along to next catch up with AP.

CMH one of our ODN projects is around improving communication and support around the time of transfer. If anyone has anything going on locally around this would love to hear.

All families now get a £10 lunch voucher, and conversations are ongoing around providing further meals later in the day.

NT inconsistent messaging and asked to ask service users for feedback. Not thought to be something service users can help with, it's for the consultants to sort out their communication, mixed messages. AD thought that parent led ward rounds could help with this. NT commented on coordinating and communicating this to parents so that they can be there. CMH made notes of things to focus on.

## NUH

NH – teddy bears picnic is on 12 September. Struggled to invite ppl because of GDPR and issues with the Facebook page. Will be moving forward with a Facebook page, with comments shut off like previously discussed.

CH

Family group going well, NH hoping CH and Tara are going to attend next week. CH confirmed.

Coffee afternoons going well, got some nice coffees, hot chocolate, and treats, and parents really pleased with these little things, gives time for them to talk. Numbers do vary.

Maisie attending health minds conference yesterday. Talked about VIG, no mention of it being used in neonates but this is really positive and really liked that idea and will look to see if this is a possibility of implementing this. JV also attended and be looking at bring in Head, Heart and Hands, principles were really good and would give a platform to manage anxieties and stressors with parents. AD would love to link in more about this if anyone happy to share their email addresses.

JV parent information guide, a booklet given out on admission and should hopefully be an easy to use, stay with them guide, and answer questions they may have, lots of the team have contributed to. Titles gone out for feedback. Will be able to bring to this group for feedback once ready.

NH accommodation, need to look at for the future. Not enough accommodation for parents to stay in new unit, it really needs to be higher on the priority list for hospitals.

HL talked about thinking outside of the box, providing reclining chairs etc. EC confirmed will be having a variety of different style chairs and these are being trialled currently. Also having a parent accommodation working group, exploring all corners of the hospital estate and wider and working on this.

## NGH

There have been some miscommunications recently around parent accommodation, going to add to parent accommodation checklist around priorities to accommodation as some parents starting to think once they are in accommodation they can stay for duration.

Maternity roadshow on 12 October which some staff will be attending to display equipment, and providing information etc

Started to offer parents who are rooming in lunch and dinner, they are given a menu the evening before to make their meal choices, as if they were an inpatient.

Family fund day event to raise money for some chairs for the unit, the day went really well.

Silver bliss accreditation in,

	Friends and family feedback – really nice for staff to get recognition.	
	LLR MNVP NT - going to be holding first 15 steps next month, excited and nervous! Decided on a weekend after speaking to parents, will see how it goes. LRI one week on Sunday the LGH the next Sunday. Happy to receive any information from others.	
	6.1 Learning from Excellence A reminder that all and any feedback is welcome.	
	6.2 Areas for Improvement A reminder that all and any feedback is welcome.	
7.	CardMedic Still live, usage is low which in part is down to the number of user accounts which were granted.	
	CH asked if there was any feedback from any units who have used with families.	
	JV feedback from a few people was that the translation was particularly good, with some confusing messages. Inaccuracies with live to translate which there will be, CMH were trying to discourage use of this. But more steering towards using the human translated cards.	
	MH to say need to think about bigger picture, can be used for dyslexia the use of sign languages and Becks has been doing some education for staff around using in NGH.	
	UHDB video translation – hopefully someone will be at the next PAG to give an update on this.	
8.	Bliss Update No update.	
9.	Unicef Update No update.	
10.	AOB  AP working on new posts for socials, once ready will email out to service user voice and parent groups for thoughts and comments.	
	CH plea to ODN restructure with new board structure, keen for it to have heavy neonatal involvement, if anyone from ODN could sit on please let CH know. CMH to email CH to catch up about this.	СМН

	Starting to look at comms around transfers if anyone would like to be involved, please get in touch with CMH. MR happy to be involved.	
11.	Date & Time of Next Meeting Thursday 05 December 2024, 6:00pm – 7.30pm, via Microsoft Teams	