

Minutes of Parents Advisory Group

Thursday 01 February 2024
11.00am – 1.00pm

Via Microsoft Teams

Present:

Cara Hobby (CMH), Deputy Lead Nurse, EMNODN (Chair)
 Julie Versteeg (JV), Family Care Sister, NUH
 Claire Gartland (CG), Maternity & Neonatal Trans Programme, Lincolnshire LMNS
 Beth Cooke (BC), MNVP Lead, Lincolnshire ICB
 Joanne Leape (JL), Parent Representative, Nottingham
 Faye Freeman (FF), Parent Representation, Derby
 Nichola Duane (ND), Nursery Nurse, LCH
 Sally Ann Simpson (SAS), FaB Lead, Lincolnshire
 Amanda Pike (AP), Parent & Family Involvement Lead, Lincolnshire ICB
 Harriet Leyland (HL), Care Coordinator, EMNODN
 Nicola Hay (NH), Parent Representative, Nottingham
 Clare Harris (CH), Independent Parent Voice Lead, Nott & Notts

In Attendance:

Linsay Hill (LSH), Office Manager, EMNODN (Minutes)

	Subject	Attachment	Action
1.	Apologies for Absence Lynsey Jones, Linda Hunn, Becky Bennett		
2.	Minutes from the Previous Meeting The minutes were passed as a true record of proceedings.	A	
3.	Matters Arising JL had messaged Sarah from Nottingham but not heard anything back. JL to pass on the details if hears back. No one from NGH present to update linking in with their peer support who started in August last year. No one from UHL present to update on the issues of Mental health support raised in last questionnaire.		
4.	PAG Membership 4.1 New Members At the last meeting spoke about looking at FiCare survey, question added would you be interested in speaking further to the Network – had a whole cohort of parents who were		

	<p>interested. Re contacted those parents, had responses from 8 who are interested. CMH and Anita D’Urso (Network Psychologist) are starting to meet with those parents to talk to them about how they can get involved. First meeting held earlier this week which went well and hoping will start to see some new parents to this group.</p> <p>CMH thanked those that supported devising the communication.</p> <p>4.2 Date/Time of Meetings Becoming clear from speaking to parents, that weekday meetings, during office hours isn’t terribly accessible, their preference is weekday evening meetings, somewhere between 5pm and 8pm. How do the rest of the group feel? Should we look at alternating? 2 evenings and 2 weekday meetings.</p> <p>SAS should be best accommodating parents and is more than happy to meet in evenings.</p> <p>JV a good idea but would be a little trickier for her to attend when working on the unit. Would need to check with management as hours not so flexible.</p> <p>FF in agreement for evenings.</p> <p>CMH summarised will trial alternating between evening and weekday meetings initially with a view moving to all evenings.</p> <p>CMH/HL/LSH to sort dates.</p> <p>4.3 Chair & Deputy Chair Group designed to be chaired by parent. Current chair is Lynsey Jones, with no deputy which means that CMH chairs LJ’s absence.</p> <p>Time to think about chair and deputy chair, previously voting process. If anyone interested, please let CMH or LJ know. Would be great to get back to the group being chaired by a parent.</p> <p>The TOR for this group the tenure is for 3 years.</p>		<p>CMH/HL/ LSH</p>
<p>5.</p>	<p>Update on HIEM Project Previously, EMAHSN. Rebranded Health Innovation EM. Group funding network to create 4 educational videos for families. To recap 4 videos: early maternal breastmilk, skin to skin, FiCare, Intro to neonatal networks. Filmed last summer, predominantly at NGH. CMH now has the draft videos for comment, CMH will share with parents, particularly those who joined the focus groups. Cannot share widely at the moment</p>		

	as some information still needs blurring out.		
6.	<p>Local Parent Feedback Want to hear all feedback, good or bad.</p> <p>6.1 Learning from Excellence In Lincolnshire there has been lots of lovely feedback, too much to share.</p> <p>6.2 Areas for Improvement SAS distraught family baby was just having antibiotics - mum anxious that dad had to leave at the end of the day – to be able to have the suite made all the difference.</p> <p>SAS Outreach Team – feedback to fab worker, supported mum to meet early years practitioner and being supported, partnership working with outreach/fab wouldn't have happened without.</p> <p>CMH asked if there was any mental health or psychology support? CMH doesn't believe there is a threshold for anyone who has had a baby on a neonatal unit even if just for a couple of hours.</p> <p>CG parent who tried to access talking therapy in Lincoln but was told she didn't meet the threshold. CMH and CG going to focus on this for Lincolnshire to ensure the criteria is addressed.</p> <p>JV been working with Clinical Psychologist, noted loophole in mental health referral process. To empower staff working with CP to create a flowchart, what does it mean to be referred. CMH suggested JV to bring to this group when ready for a soft launch.</p> <p>BC went to LCH and met with Rachel Wright (Acting Neonatal Matron) to talk about how collecting feedback. Looking to work together to create a combined one. 9 core theme questions</p> <p>CMH/HL did some scoping – feedback from units that struggle to get feedback. BC to present this in future. Be useful for BC to link any questions with Anita D'Urso.</p> <p>HL talking about trigger points for questions. BC is anyone doing this in practice at the moment – HV big push to make sure feedback is given at any point. SAS knows that the FaB workers do this, and parents are encouraged to write this down.</p> <p>JV said JL also collects this feedback from parents on the units.</p>		

FF how is feedback collected for people who don't have access to technology and also non-English speaking. BC QR code will take to landing page which will have the top 8 languages.

JV - positive feedback – parents feel really involved in their baby's care.

There's some work around communication making sure certain things are handed over between nursing staff. JV going to be doing some audits around handover processes.

NUH parents loving OPUS who come in every couple of weeks!

JL – really great positive feedback recently about staff, smiley staff being asked if ok, makes a real difference. JL get lots more information in the parent rooms rather than at the cot side. JL has been asked if there will be staffed sibling room? JV confirmed there will be a sibling room, but it won't be staffed.

CMH mentioned sibling groups in other units and maybe look at sharing this at this group. Nationally app being developed for siblings, almost like a video game.

HL – PICU sensory room. 3D tours starting to get off ground, sibling element to look at – easter egg hunts etc, could be seasonal.

NH still running coffee mornings – NH and JL did one this week, trying to build up, new ideas to get people involved. 18 mums and babies at Trent Vineyard babies approaching 12 months. Group may be a good place for MNVP to come – Clare Harris could maybe link in around what could be done there.

NUH journey beads - going to do another launch end of this month – hoping this will increase coffee morning attendance.

JV asked if parents would prefer that the family care team were present at these, would it be more comfortable if they only attended for a short period of time? AP said found more honest conversations with no staff. CMH also found this from parent feedback. Maybe MNVPs could better support.

CH just waiting to visit city and is waiting to hear from Pippa. CH runs Emily Harris Foundation at KMH, runs coffee morning with charity hat on, but clear about other role. Recent comments around language or medical language is used. Family been in NUH, staff trying to put long line in said not going to make it, they meant long line but family thought they

	<p>meant the baby. Leicester family transferred to KMH, baby in Level 3 in UHL, mum thought this was in the same hospital, and that they were just talking a different ward.</p> <p>CMH responded that part of the Network role is to try to reduce differences in units and can work with CH on. Our strength will be around linking in with parents and MNVPs. For example, meals; picked up in peer reviews, but good to have the parent voice for equity of services.</p> <p>Support units to include family in transfer discussions and hopes the videos will help with this.</p> <p>Also a Network prompt card for transfers.</p>		
7.	<p>CardMedic Communication and Translation tool. Nottinghamshire LMNS have supported the Network by funding 12-month subscription to trial CardMedic.</p> <p>In process of recruiting unit champions and setting up meeting with CardMedic</p> <p>Communication perceived by parents and staff as the biggest barrier to equitable care. Will support units to audit.</p> <p>Coming up with phrases, will be going through a project steering group where we'll look to have parent representation.</p> <p>Languages Neurodiverse BSL</p> <p>CardMedic is all human translated.</p>		
8.	<p>Bliss Update What is it that parents would feel helpful to hear on this.</p> <p>CMH still working with units to progress baby charter standards. Going slower, units struggle to provide protected time for staff to take this forward. Bliss in process of developing FiCare framework, piloted at Luton & Dunstable with the hope it will become a national framework.</p> <p>CMH could ask Bliss to come to this meeting to do a presentation or provide an update.</p>		
9.	<p>Unicef Update Still working with units to progress the neonatal standards. HL working with Infant Feeding links on Baby friendly accreditation.</p>		

	Supporting units with business cases for infant feeding links.		
10.	AOB 10.1 Families Engagement Lead Full time Band 7 post, on NHS jobs and also NGH jobs board. Hopeful this role will take on a lead with this group but will see how this progresses.		
11.	Date and time of next meeting Thursday 02 May 2024, 6:00pm – 7.30pm, via Microsoft Teams		