

**Minutes of Parents Advisory Group**

**Thursday 02 May 2024**  
**6:.00pm – 7:30pm**

**Via Microsoft Teams**

**Present:**

Cara Hobby (CMH), Deputy Lead Nurse, EMNODN (Chair)  
Harriet Leyland (HL), Care Coordinator, EMNODN  
Amanda Pike (AP), Parent Engagement Lead, Lincolnshire ICB  
Nicola Hay (NH), Parent Representative, Nottingham  
Clare Harris (CH), Independent Neonatal Parent Voice Lead, Nott & Notts MNVP  
Rachael Adams (RA), Fab Worker, LCH  
Nafeesah Tutla (NT), Neonatal Co-Lead, MNVP, LLR  
Nicola Malazzab (NM), FiCare Lead, NGH  
Michelle Hardwick (MH), Matron, NGH  
Matt Rutter (MR), Parent Representative, NGH, RDH & QHB

**In Attendance:**

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

	<b>Subject</b>	<b>Attachment</b>	<b>Action</b>
1.	<b>Apologies for Absence</b> Lynsey Lord, Rachel Wright, Rhian Cope, Zara Doubleday, Beth Cooke, Sally-Ann Simpson, Joanne Leape		
2.	<b>Minutes from the Previous Meeting</b> The minutes were passed as a true record of proceedings.	<a href="#">A</a>	
3.	<b>Matters Arising</b> <ul style="list-style-type: none"> <li><b>NGH Peer Volunteer</b> CH gave explanation of Peer support. If anyone interested get in touch with the ODN team who can put you in touch with the staff on the unit. NM confirmed Maddison is the peer volunteer, could NM speak to Maddison to see if interested in coming to PAG at the next coffee morning.  MR would be interested in learning more.</li> <li><b>Mental Health Support at UHL</b> Progressing as previously raised in parent feedback as something that was needed. NT confirmed they have a mental health group set up and is something they are working on but not heard anything from the unit specifically. CMH to put unit rep in touch with NT.</li> </ul>		<b>CMH</b>

<p><b>4.</b></p>	<p><b>PAG Membership</b></p> <p><b>4.1 New Members</b>  CMH welcomed all new members, and please feel free to ask questions, share experiences during the meeting or via email which CMH can pick up outside of meeting.</p> <p><b>4.2 Date/Time of Meetings</b>  Having this meeting in the evening is new for us. This was the preference of parents. We will initially alternate between one evening meeting and one lunchtime meeting and would be keen to hear any thoughts on this. Will review this after a year.</p> <p><b>4.3 Chair &amp; Deputy Chair</b>  Mentioned at previous meeting, the group is designed to be chaired by a parent. Current chair has been in post for 14 years, she is however finding it difficult now to commit the time, CMH chairs in Lynsey absence at the moment. The ODN have now appointed to Parent &amp; Families Engagement Lead, and they will be ideally placed to gradually take over the chairing of PAG initially.</p> <p>AP will be joining the Network in June as our Parent &amp; Families Engagement Lead so all will be seeing a lot more of her in future. AP has been the Lincolnshire Chair since 2019, which was the first NVP in the country.</p>		
<p><b>5.</b></p>	<p><b>Update on HIEM Project</b>  Health Innovation East Midlands provided funding to the Network to create 4 educational videos for families. Early maternal breastmilk, skin to skin, FiCare, Introduction to neonatal networks. These were filmed last summer, predominantly at NGH.</p> <p>The videos are now in the final editing stages and hoping that they are ready to share before the next meeting.</p> <p>The need for these videos came from the PAG group, differences in information given between units, and that it would be helpful to create network wide resources. They will be hosted on our website and shared on our social pages.</p>		
<p><b>6.</b></p>	<p><b>Local Parent Feedback</b>  CMH explained that all and any feedback is welcome.</p> <p><b>NGH</b>  holding two neonatal and TC listening events and are hoping these go well. Giving out flyers on discharge and to parents on the unit and sharing on their socials.</p> <p>Parent accommodation: 2 twin rooms now, being used and hoping to get some feedback on those too.</p>		

<p>Coffee mornings back up and running.</p> <p>Mel the Psychologist devising a leaflet for parents.</p> <p>CMH hoping to organise some ODN level listening events when AP comes into post.</p> <p>HL has shared the NGH listening information on the ODN Instagram</p> <p><b>NUH</b> NH updated on project in NUH with Family Care Sister, increasingly there are more people coming from outside of Nottingham and so devised a display board, with local walks, entertainment, supermarkets etc and this has received really good feedback.</p> <p>Introduced journey beads, which are beads for milestones; breastmilk, CPAP and this has been really good.</p> <p>Still running the family group with about 15 families regularly attending.</p> <p>The Network have a quarterly family matters newsletter, spotlighting good FiCare practice and would love to include these innovations in next newsletter, NH agreed and will send CMH photos of board. CH agreed the boards were fabulous and will be looking to replicate these in KMH.</p> <p><b>KMH</b> CH ongoing discussed regarding meal provision in KMH, Trust don't currently provide meals for parents, and working to get this changed. CH has noticed on walk arounds that nowhere in antenatal units mentions neonatal services, looking at producing a poster for these areas to prepare families without scaring them. If anyone has posters in their antenatal areas would be grateful if these could be shared. CMH has a poster that was devised by the West Midlands, with permission to adopt and is happy to share this with CH.</p> <p>CH talked to family with baby in City and then transferred to KMH. They fedback that doctors' communications were very good at City and that consultants on ward rounds had lots of time to explain what happening with baby.</p> <p>Issues with medications being missed for mums at KMH and CH is working with Matron on ways to improve this.</p> <p>MR really liked the idea of the information board with local information. MR really loved the journey beads, and explained that the cards, gifts etc are great for memory boxes.</p>		<p><b>NH</b></p> <p><b>ALL</b></p> <p><b>CMH</b></p>
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	<p><b>NGH</b>  MH explained that maternity have done road show and will be involved neonatal team in the next one, taking incubator down.</p> <p>NT discussed maternity roadshow today after seeing NGH poster. So really helpful to see that and think about. MH to share NGH contact with NT.</p> <p>AP in Lincolnshire held what matters events, held all over the county. Lots of service providers attended. AP happy to link with people and share ideas.</p> <p>CMH explained that ODN team are available to support events if anyone would like our involvement and suggested getting the MNVPs involved too.</p> <p>NT carparking – chatting about adapt community group. A priority for HL to discuss at meeting next week car parking to try to tackle this issue. Unit were putting together a business case, not been agreed and unsure what else they can do. Ch wasn't sure that shed seen the latest business case but would be happy to add to this.</p> <p>CMH/HL to contact TP about business case.</p> <p>CMH to make sure parking has been escalated through the ODN representative at LMNS.</p> <p>CMH and HL will have Ficare Survey Results to share at the next meeting. Feedback given to units and this group, see if there are any areas for projects for this group.</p> <p><b>6.1 Learning from Excellence</b>  A reminder that all and any feedback is welcome.</p> <p><b>6.2 Areas for Improvement</b>  A reminder that all and any feedback is welcome.</p>		
7.	<p><b>CardMedic</b>  Communication and Translation tool. Nottinghamshire LMNS have supported the Network by funding a 12-month subscription to trial CardMedic.</p> <p>Trial is now live across the region. App and web based can translate into 49 difference languages, human translated. Can also support accessibility, text, size, colour, read aloud, basic sign language.</p> <p>Hoping to see it used to promote more equitable care, particularly for those who don't speak English as their first language.</p>		

	<p>Whole bank of neonatal content.</p> <p>4 users on each site to use for next 12 months. 4 units now have unlimited access to CardMedic as their Trusts have purchased; KMH, NUH and NGH.</p> <p>We can take suggestions to CardMedic for new scripts. Would be great to hear from parents around useful phrases, what found helpful. Any parents interested in getting involved please reach out to CH/HL who can further discuss how this can. Monthly meeting with CardMedic champions, at these meetings assessment progress, seeing if used, get family feedback.</p> <p>MR raised the issue of dyslexia and the use of BadgerNet.</p>		
8.	<p><b>Bliss Update</b></p> <p>Still working with units to progress. One unit has registered intent to achieve standards, 8 units at Bronze and 3 units at Gold.</p> <p>Any parents interest in family centre care and would like to help with the process get in touch.</p> <p>Bliss released data on parent accommodation across the country. For every 10 baby there is only 1 room for parents to stay in. Will include a link in the chat.</p> <p>Bliss are doing a campaign to improve facilities across country so can add your name to show support. For those involved in speaking to other parents please do share with other groups.</p> <p>Please read with caution and get in touch if need any support.</p>		
9.	<p><b>Unicef Update</b></p> <p>Network have provided funding for each unit to achieve Unicef BFI neonatal specific standards. These are all around parents having close and loving relationships with babies, breastfeeding culture and support, parents as partners in care, if anyone would like to support local units in achieving this, please get in touch with CMH.</p>		
10.	<p><b>AOB</b></p> <p>NT has been invited to stork stakeholder event, is this something that is regional or just UHL. CH confirmed not regional and as far as know UHL are only unit taking it on. TP was very much involved in the early creation and introduction of the programme.</p> <p>NH in NUH had problem with FB, have difficulty now advertising events and they have created a wish list for hospital.</p>		

	<p>NH asked for ideas on sharing information as the NUH Facebook closed down. MNVP has social pages which may help.</p> <p>CH confirmed MNVP have Facebook page and happy to share information.</p> <p>KMH do have successful page which is very well regulated.</p> <p>AP linking with Childrens Centres, breastfeeding groups, community groups with posters.</p> <p>MR suggested units could use FB events to advertise listening events, fundraising etc.</p>		
11.	<p><b>Date &amp; Time of Next Meeting</b>  Thursday 05 September 2024, 11:00am – 12.30pm, via Microsoft Teams</p>		