

Minutes of Parents Advisory Group

Thursday 22 May 2025
6:00pm – 7:30pm

Via Microsoft Teams

Present:

Amanda Pike (AP), Parent & Families Engagement Lead, EMNODN (Chair)
Harriet Leyland (HL), Care Coordinator, EMNODN
Nicola Hay (NH), Parent Representative, Nottingham
Nafeesah Tutla (NT), Neonatal Co-Lead, LLR MNVP
Nicole Malazzab (NM), FiCare Lead & Governance Lead Nurse, Northampton General Hospital
Vicky Enfield (VE), Parent Representative, Northamptonshire MNVP
Claire Houghton (CEH), FiCare Lead, Kettering General Hospital
Sally-Ann Simpson (SAS), Lead FAB Worker, United Lincolnshire Teaching Hospitals
Beth Cooke (BC), MNVP Lead, Lincolnshire
Clare Harris (CH), Independent Neonatal Parent Voice Lead, Nottingham & Nottinghamshire MNVP
Michelle Hardwick (MH), Matron, Northampton General Hospital
Isabelle Reed (IR), Parent Representative
Lois Warren (LW), Parent Representative

In Attendance:

Faye Kitcherside (FK), Administrator, EMNODN (Minutes)

	Subject	Attachment	Action
1.	Welcomes & Apologies for Absence Gemma Manning (GM), Maisie Partridge (MP), Michelle Pashley (MP), Sarah Roberts (SR).		
2.	Minutes from the Previous Meeting The minutes were passed as a true record of proceedings.	A	
3.	Matters/Actions Arising Any actions or matters arising will be covered in the agenda.		
4.	Birth in the Right Place AP explained that some parents find the term 'birth in the right place' upsetting. When families require a transfer, the term can make them feel as if it is their fault when they are not in the most appropriate place. MH understood how this can affect parents. BC agreed and explained that this term unintentionally blames parents for situations out of their control.		

	AP will discuss this issue with families on a wider scale to gather their thoughts and how the language could be changed to be more supportive.		AP
5.	<p>Website Unit Information</p> <p>The Network Team are in the process of refreshing the website and would like to ensure that families can access all of the information that they feel necessary. AP asked the group to take some time to look at the information available (Neonatal Care East Midlands Neonatal Operational Delivery Network (EMNODN)) and to provide any feedback on what is, and is not, helpful</p> <p>NT is working on a Padlet which covers information for parents. HL will explore whether it would be possible to add unit Padlets to the Network website.</p> <p>NH also reported that a Baby Facts Information Book is being developed and will share with the group once finalised.</p>		<p>ALL</p> <p>HL</p>
6.	<p>PAG Design: Options/PAG Packs</p> <p>AP explained that she would like to get more families involved in the PAG from across the East Midlands to ensure there is a diverse representation.</p> <p>AP shared her objectives, which are as follows:</p> <ul style="list-style-type: none"> • Increase family membership • Improve diversity • Raise the PAG profile • Introduce PAG champions • Create PAG bulletins <p>AP plans to create three different PAG packs, one for parents prior to becoming a PAG member, one for parents once they have decided to become a PAG member, and one for professionals such as those in the units, homecare teams, hospice workers etc, who may be interested in joining PAG, becoming a champion, or taking part in promotions.</p> <p>AP also discussed possible ways to promote PAG, for example through posters in a variety of different settings, such as GP surgeries, children's centres, through articles, and the radio.</p> <p>Additionally, AP discussed developing a PAG roadshow which visits neonatal units, faith groups, and community groups.</p> <p>AP would like to develop a new PAG specifically for bereaved parents. The name 'Little Stars' was suggested but this would be agreed with families first. AP will speak to families to agree how often the group would run.</p>		

	<p>Another suggestion was creating PAG champions and identifying PAG badges. AP plans to create a 'PAG Tag' – which is a mission statement outlining the group objectives in simple terms. This could be applied to PAG promotional items.</p> <p>AP would like to create PAG awards to celebrate all the amazing PAG work being carried out across the East Midlands. This would hopefully be empowering, and families would be invited to celebrate those who have helped, from neonatal nurses to parents who have contributed.</p> <p>AP believes that the PAG needs refreshing to become more effective and accessible. She suggested five options as follows and then asked for the group's thoughts:</p> <ul style="list-style-type: none"> • Option 1: The meetings carry on as they are, but AP continues to try to expand the family volunteers to ensure broader representation • Option 2: The meetings will be changed slightly so the first part is for families only. Professionals will be invited to join the second half and families can choose to stay or leave at this point • Option 3: There are two separate meetings, one for families and one for professionals • Option 4: The PAGs are entirely family led with periodic feedback provided to professionals • Option 5: Regional smaller PAGs feeding into a central PAG. The smaller PAGs would be held by the PAG champions <p>CEH liked the idea of option two as she believes it will encourage families to open up more. Additionally, CH supported the idea of the 'Little Stars PAG'.</p> <p>NH reported that the PAGs used to consist predominantly of parents, however over time parental engagement has reduced. NH offered to help with any ventures that will increase parental PAG participation.</p> <p>BC asked the group why they believe that it is challenging to get parental involvement. IR suggested that some parents find it very hard to talk about their experiences as they were incredibly challenging and overwhelming. IR also reported that she is aware that some parents find it intimidating being in meetings with health professionals.</p> <p>NT explained that some parents who feel able to discuss their experiences already do so at MNVP meetings, and so perhaps may not see the need to attend PAG meetings as well. NT also added that HL attending some MNVP meetings has been useful as it adds another perspective and also reminds parents of PAG.</p>		
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	SAS felt that she would like to see parents remaining involved in the meetings with professionals as they provide so much insight that may not have been considered otherwise.		
7.	Local Parent Feedback 7.1 Learning from Excellence Not covered. 7.2 Areas for Improvement Not covered.		
8.	National Scheme Updates 8.1 Bliss HL briefly outlined the Bliss Baby Charter, which is an accreditation programme which neonatal units work towards, at different levels (bronze, silver, gold and platinum). NGH have received their gold accreditation and will be receiving their gold plaque in the next few weeks. 8.2 UNICEF BFI is the 'Baby Friendly Initiative' which supports infant feeding, and promotes close and loving relationships between parents and babies on neonatal units. This can be more complicated for units to achieve than Bliss Baby Charter, but a couple of units are looking to complete their Stage 2 this year.		
9.	AOB NH spoke on behalf of MP who was not able to attend. NUH are reinstating complimentary therapy (massages etc), for parents, which was very popular pre COVID. There will also be a Teddy Bears picnic in September. CH asked to connect with NH outside of the meeting as she would like to introduce complimentary therapy through The Emily Harris Foundation at KMH. CH updated the group around transitions and transfers where a baby has been on a neonatal unit but is 44+ weeks old and will consequently be eligible for a cot on the paediatrics/children's wards. Focus groups are needed to understand parents' experiences of these transfers and how they can be improved. CH highlighted that experiences do not need to have taken place in Nottinghamshire. Once the focus group dates have been finalised, HL/AP will share. HL reported that the Network Team are looking to create a transfer animation video for families and would like family input to ensure that the necessary information is captured within the video.		HL/AP

	<p>NT raised the issue of free parking, which has generally been very positive for parents at UHL, she has been made aware that this is only eligible for one car per family. NT enquired if this is also the case in other Trusts. HL believes that other units allow two cars and is happy to talk to the UHL team to see if this can be changed alongside the existing issue of having to renew parking after 17 days.</p> <p>LW also suggested targeting charities to increase PAG attendance which the group all agreed was a great idea.</p>		
10.	<p>Date/Time of Next Meeting 18 September 2025, 11:00am – 12:30pm, via Microsoft Teams</p>		