

Minutes of Parents Advisory Group

Thursday 05 December 2024
6:00pm – 7:30pm

Via Microsoft Teams

Present:

Amanda Pike (AP), Parent & Families Engagement Lead, EMNODN (Chair)
 Harriet Leyland (HL), Care Coordinator, EMNODN
 Beth Cooke (BC), MNVP Lead, Lincolnshire ICB
 Nicola Hay (NH), Parent Representative, Nottingham
 Nafeesah Tutla (NT), Neonatal Co-Lead, LLR MNVP
 Michelle Hardwick (MH), Matron, Northampton General Hospital
 Nicole Malazzab (NM), FiCare Lead & Governance Lead Nurse, Northampton General Hospital
 Michelle Pashley (MP), Neonatal Co-chair, Derby & Derbyshire ICB
 Hannah Copley, Parent Representative, Nottingham

In Attendance:

Linsay Hill (LSH), Office Manager, EMNODN
 Faye Kitcherside (FK), Administrator, EMNODN (Minutes)

	Subject	Attachment	Action
1.	Welcomes & Apologies for Absence Rebecca Bennett (RB), Sally-Ann Simpson (SAS), Louise Bakin (LB), Lynsey Lord (LL), Rachel McCoy (RM), Anita Durso (AD), Cara Hobby (CMH), Claire Harris (CH), Julie Versteeg (JV), Joanne Leap (JL)		
2.	Minutes from the Previous Meeting The minutes were passed as a true record of proceedings.	<u>A</u>	
3.	Matters/Actions Arising NH has sent photos of the display board to HL. The West Midlands neonatal posters for display in antenatal areas have been shared with NT and CH. NT confirmed she has received. CH is going to send suggested dates to introduce AP. CH had asked in the last meeting for some representation from the EMNODN on their Board. As CH and CMH were both unavailable, this will be picked up at the next meeting.		CH CH/CMH

4.	<p>Update on HIEM Project</p> <p>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.</p> <p>HL confirmed that the videos are still going through the editing process. They will be shared when available. HL also confirmed there is a recruitment video which was filmed in Leicester and will be shared once finalised.</p>		
5.	<p>Local Parent Feedback</p> <p>5.1 Learning from Excellence</p> <p>Derbyshire</p> <p>No recent feedback. 15 steps will be undertaken at QHB in February. MP will let the group know when they are looking for parents to assist with this.</p> <p>LLR</p> <p>NT confirmed that the 15 steps went well, and received lots of feedback which is being collated into a report - NT hopes she will be able to share in the new year. NT explained that feedback from parents shows that mental health support post discharge needs improving. As a result, NT has highlighted in numerous meetings and is pleased it is being looked into to see what support can be offered. Psychologists are available on the unit in Leicester but only work part-time.</p> <p>NT also explained that expressing/breastfeeding support has recently been highlighted as an area for improvement and will be discussing at their NVP meeting next week. She explained that nursery nurses are generally good at providing this support, but it does not always feel like a priority for other staff.</p> <p>NT explained that the importance that parents put on breastfeeding/expressing needs to be clear so that they are well supported especially when sometimes they are separated from their baby. This is another area that they are focusing on.</p> <p>NT also confirmed that they have pushed for free car parking in Leicester. HL asked NT why parking is free for only 17 days as many babies will be in hospital for longer than this. NT wasn't aware of this and will raise at a meeting next week.</p> <p>Lincolnshire</p> <p>Babies being separated from their families is causing a deep impact. BC shared data collected from surveys based around neonatal care in Lincolnshire. She confirmed the reoccurring theme was babies being separated from their parents. BC offered to share these surveys as a PDF for anybody interested.</p>		

BC also explained that it can be difficult for neonatal parents to find the time to complete surveys. She also explained that there is a QI project being undertaken which looks at training midwives to become 'second checkers' for neonatal antibiotics, allowing babies to receive antibiotics at the maternal bedside and reducing separation. Current practice is that babies attend the neonatal unit, sometimes without parents, for their antibiotics. BC also discussed the use of neonatal and maternity huddles which have enhanced communication between teams.

NT agreed with BC and explained they have received the same feedback with regards to babies and parents being separated. NT provided an example of babies being taken away from the parent to have antibiotics administered. NT explained that they are looking at creating transitional care units, hopefully on the post-natal ward, but there is not much space in Leicester to do so. NT also explained that there is a lack of communication, and parents are unaware that they can ring/speak to the neonatal unit. She feels that neonatal huddles including families would be helpful.

HC shared her experience of having her son via planned c section, she went onto a normal post-natal ward where other parents were there looking after their babies. She explained she received a photograph but felt the ward didn't communicate with her. She felt like the 'odd one out'. She suggested using separate bays for parents like her who have just given birth but do not have their babies there with them.

NH explained that in NUH, when babies require antibiotics, parents are allowed to come to the unit, but this practice stopped during COVID, and it has been hard to reestablish. The ideal solution would be bays of four with other NICU parents. She said that the new unit in Nottingham will hopefully help. NH also explained that they are running coffee mornings which helps parents to find out more information (e.g. around car parking).

AP asked for more information from NH regarding coffee mornings. NH said common themes coming from these coffee mornings is that staff provide different information and breastfeeding advice changes depending on the staff member. As communication between staff and parents comes up a lot during these meetings, it allows feedback to be provided to the ward manager/family care team to stop these issues escalating further. NH explained that during the coffee morning, parents are given the opportunity to participate in arts and crafts.

HL commented that work needs to happen for situations where it is known pre-birth that babies are going to be in NICU. She

	<p>said it is hard to organise bays specifically for parents with NICU babies as this can result in a lot of moving around but it is worth discussing it with maternity to try and ensure this happens where possible.</p> <p>HL also wanted to highlight the amazing work that NH does and how much of a lasting impact this has on families.</p> <p>NM explained that in Northampton the Psychologist has been extremely helpful and is providing training for doctors, nurses and HCAs to help with more difficult conversations with parents. There are 2 new ward volunteers working different days with primary objective of talking to families. They have also organised a coffee morning. There are two overnight rooms for parents, as well as free food and a snack stand available. MH added that the psychologist has also set up bi-weekly listening events at a local community centre for parents. Parents can book onto these sessions using a QR code. Another listening event will hopefully be planned for June and flyers will be available approximately 3 months before.</p>		
6.	<p>CardMedic</p> <p>HL explained that CardMedic is an app which is being trialled across all units with the aim of supporting translation. There are pre-written cards on the app which parents can translate into their chosen language. There is a read aloud version. HL explained that the trial is due to end in January/February when it will be assessed whether it will continue or not.</p> <p>HL explained they are struggling to get feedback from units. She also explained that logins are restricted to 4 units apart from in Nottingham and at King's Mill.</p> <p>MH confirmed they are still using CardMedic at NGH and have received some positive feedback. They are looking into getting it Trust wide.</p> <p>HL explained that the app is working well when units are taking the time to look at the content before they are in a situation where it needs using. She reiterated it is not to replace translators and warned against using the live translate function due to potential inaccuracies as that component is not human translated.</p> <p>MH fed back to the group that the app has successfully helped a mum to express breastmilk.</p> <p>HL also discussed VCreate which offers translation, videos and communication for parents. HL is exploring VCreate for the units, but it is expensive.</p>		

	<p>MH explained that they have looked into VCreate but as it is expensive it would have to come out of charity funds. Therefore, they have found that BadgerNet works well for them, but they struggle with lack of IT expertise.</p>		
7.	<p>Bliss Update</p> <p>HL gave a brief overview of the Bliss Baby Charter which is a family centred care style charter that the ODN supports units to implement. It is an assessment with different levels; bronze, silver, gold and platinum. There are criteria for each level and units upload evidence of how they are meeting this.</p> <p>HL explained that many of the units are working towards the Bliss Baby Charter, most are at bronze. It is a lengthy process with several principles.</p> <p>HL congratulated NGH on their recent silver accreditation and highlighted that Bliss were very impressed with them and have encouraged them to apply for gold status next year.</p>		
8.	<p>UNICEF Update</p> <p>BFI is the 'Baby Friendly Initiative' which supports infant feeding and promotes close and loving relationships on neonatal units.</p> <p>HL explained that previously, midwifery and neonatal standards were combined but have now moved to a separate neonatal accreditation. The ODN has banked funds with UNICEF to support units in reaching stage 1.</p> <p>KMH have completed all stages of BFI.</p>		
9.	<p>AOB</p> <p>NH explained that they raised £600 for World Prematurity Day.</p> <p>NM explained that MH and KM (Ward Manager) attended the NGH Maternity Road Show for pregnant people and discussed what would happen if they gave birth prematurely. They took incubators and have since seen some of these parents on the neonatal ward, so it was very helpful.</p> <p>NM also explained NGH have revised their siblings' visiting policy and now support siblings to visit the ward 24/7 (previously it was 12 – 4pm only).</p>		
10.	<p>Date/Time of Next Meeting</p> <p>Thursday 06 February 2025, 11:00am – 12:30pm via Teams</p>		