

Minutes of Parents Advisory Group

**Thursday 27 January 2022
11.00am – 1.00pm**

Via Microsoft Teams

Present:

Lynsey Jones (LJ), Parent Representative, Nottingham (Chair)
 Linda Hunn (LH), Director/Lead Nurse, EMNODN
 Cara Hobby (CH), Deputy Lead Nurse (FiCare & PPI), EMNODN
 Haddie Borbely (HB), Care Coordinator, EMNODN
 Julie Versteeg (JV), Family Care Coordinator, NUH
 Phillippa Nash (PN), Family Support Deputy Sister
 Mikila Round (MR), Family Care Sister, NUH
 Nicola Hay (NH), Parent Representative, Nottingham
 Joanne Leape (JL), Parent Representative, Nottingham
 Sarah Kent (SK), Matron, Kettering General Hospital
 Rachel Wright (RW), Ward Manager, Lincoln County Hospital
 Sally-Ann Simpson (SS), FaB Worker, ULHT
 Denise Mountain (DM), Outreach Sister, UHDB
 Becky Knight (BK), Neonatal Outreach Nurse, UHDB

In Attendance:

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

	Subject	Attachment	Action
1.	Apologies for Absence Linda Hunn, Claire Gartland, Gemma Manning, Jo Vickers, Becky Bennett		
2.	Minutes and Actions from The Previous Meeting The minutes were passed as a true record of proceedings.	A	
3.	Matters Arising LSH to circulate a copy of the PPI governance structure to the group for information. Any queries to CH.		LSH ALL
4.	COVID-19 4.1 Parent Access and Visiting It is has been reported to the Network that each unit is facilitating 24-hour unrestricted access for parents however this isn't strictly the case in some units, with some operating one visit per 24-hour period, only 1 parent and rota systems. The Network are still trying to pick up the issues with the		

	<p>National IPC team and CH reassured all that this matter is still on the radar. A small proportion of units are supporting parents to have mask free time with their babies although this is inconsistent across the region. CH asked if anyone has been successful in procuring clear masks.</p> <p>All units reporting that parents are testing twice per week with the exception of two units who are testing once per week.</p> <p>NUH are asking everyone on the unit to complete daily lateral flow tests and show results, in addition to a symptom check list. For parents' it truly is now unrestricted access. Transparent masks are still work in progress as there are supply issues.</p> <p>In RDH parents are asked to twice weekly LFT, access has changed to unrestricted. Due to the available space on the unit it is possible to facilitate mask free time.</p> <p>In KGH there are no access restrictions for parents. Mask free time is being facilitated. SK reported that the clear masks are really uncomfortable to wear. Parents are asked to twice weekly LFT and show results.</p> <p>4.2 Face Masks Covered above.</p> <p>4.3 Parent Testing Covered above.</p>		
5.	<p>Patient and Public Involvement (PPI)</p> <p>5.1 Neonatal Voices</p> <p>Not a huge amount to update on, an event was held back in September 2021 which showcased the Lincolnshire model which went really well. Derbyshire & Leicestershire LMNSs have taken on this approach and are now starting to recruit for their NVPs.</p>		
6.	<p>Family Integrated Care (FiCare) Project Update</p> <p>6.1 Link Nurses</p> <p>Link nurses are still in post, with nothing new to report. There have been struggles to get hours in at the moment due to clinical pressures, but CH/HB continue to work with units to support.</p> <p>6.2 Steering Group Update</p> <p>The minutes from the December FiCare Steering Group were shared with LJ as PAG chair. The main focus has been on discharge tools for parents and the creation of a prompt or crib sheet for staff to ensure a family's circumstances are considered when making decisions around transfer.</p> <p>LJ will continue to have sight of the minutes from the FiCare</p>		

<p>Steering Group.</p> <p>6.3 Posters The Network posters have been refreshed and sent out to units for display, the posters are also available on the new Network website.</p> <p>6.4 NUH Discharge Tool and All About Me At the last meeting some documents were shared for PAG review around discharge and all about me tools. The NUH link nurses are currently exploring different options and will be holding a specific parent focus group. Anyone interested in being a part of that to contact JV/CH.</p> <p>6.5 ReCite Me & Leaflet Translation Update The Network trialled ReCite Me software and although initially promising it was decided not to go ahead with purchase due to concerns around the accuracy of translations.</p> <p>The Network will be funding the translation of 20 parent leaflets into the top 5 languages across the region. Once completed these will be made available on the website.</p> <p>6.6 EMNODN FiCare App The Network are going to be developing a FiCare App alongside with Dr Pillay from UHL. Dr Pillay will have a slot at the FiCare Steering Group to give more detail around this. It is likely that there will be some small focus groups initially to look at and decide upon App content.</p> <p>6.7 Family Matters Social Media Been looking at presence on social media to better engage with parents specifically around FiCare. Initial thoughts are around creating video content for the current competencies/teaching packages for example, bathing, taking temperatures etc and having these videos available on various platforms for parents to watch.</p> <p>JV understands there is a consultant in NUH who is also looking at developing something similar. JV to put in touch with HB/CH</p> <p>DM mentioned a parent craft video they have on the postnatal ward in Derby and thought something similar might be worthwhile.</p> <p>JV explained that in NUH they are looking to include parent teaching on vCreate and thought it may be worth DM considering grant funds for purchase of vCreate in Derby. JV to share vCreate contact with DM.</p> <p>The parents present thought that videos would be a great idea, and definitely something they would have liked to have had</p>		<p>ALL</p> <p>JV</p> <p>JV</p>
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	<p>available. It was also felt that this would help families whose first language isn't English, those who are dyslexic and those who simply learn better in this way.</p> <p>SK said video designed at UHCW, for kangaroo care which was displayed on a loop in the intensive care room.</p>		
7.	<p>Bliss Update 7.1 Charter Audit & Accreditation Update The Network have funded gold accreditation for all units. CH/HB are working with each of the FiCare links and Hollie Sullivan at Bliss to support this.</p> <p>Currently there are 2 x Gold units, 7 x Bronze units, 1 x Pledge unit and 1 registered intent unit.</p> <p>HB explained that it may be worth units involving their FiCare link nurses in the Bliss audit accreditation where this isn't already the case.</p> <p>LJ raised the potential issue of visibility of accreditation levels in units and how this could be perceived by parents. CH/HB to go back to establish what units are displaying.</p> <p>There was lots of discussion around whether or not units should display their accreditation status. It was agreed that some explanation of what the accreditation means was essential to go alongside. CH/HB to look at.</p>		<p>CH/HB</p> <p>CH/HB</p>
8.	<p>Unicef Update CH/HB working with units around BFI accreditation. The Network have funded 1 individual from each unit to undertake the 5-day BFI training, and hoping to see some progress/improvement made on the back of individuals attending.</p> <p>The Network have also funded access to the baby friendly eLearning tool for 1 paediatrician from each unit having funded BFI leads to attend the UNICEF BFI conference in November 2021.</p>		
9.	<p>Outreach Update and Proposals for 7/7 A 7-day outreach service was one of the mitigations for critical care capacity across the Network. A plan on a page and business case was resubmitted to Specialised Commissioning with a view to receiving funding for this in the next financial year. The business case has gone to second stage but no further update has been received on that yet.</p>		
10.	<p>Pre Term Birth Group 10.1 Extreme Preterm Parent Information This information has been significantly revised following comments from some clinicians. CH is hopeful that it will be</p>		

	<p>ready in draft form to come out to this group in February for comment.</p> <p>Of the exception reports that were reviewed for the <27/40 babies that were not born in a maternity unit collocated with a NICU, change could only have been effected on 3% in order to facilitate a tertiary centre birth.</p> <p>10.2 Transfer Information Parent Information Some minor amendments have been made to the transfer parent information leaflet, an updated leaflet can be viewed here.</p>		
11.	<p>National Feedback</p> <p>11.1 Neonatal Critical Care Transformation Review Update Not enough critical care capacity within the East Midlands work is ongoing with UHL and NUH around long term new build projects and increasing capacity and also some short-term solutions.</p> <p>Awaiting formal outcome of national nurse staffing funding.</p> <p>Network AHP roles have been recruited to with exception of SLT. They will be starting at varying points over the next few months. A plan to address SLT provision is being work on.</p> <p>11.2 Care Coordinators Group Update All now in post across each Network in the country. The group at the moment is still in its infancy.</p>		
12.	<p>Local Group Updates & Feedback JV reported that NUH have restarted coffee mornings and have had some really positive feedback.</p>		
13.	<p>Network Update Really struggling for capacity recently, compounded by COVID related staffing absences. The Network and unit teams continue to meet weekly to understand the pressures.</p> <p>New Deputy Lead Nurse with a particular remit for Quality & service improvement will be starting with the Network on 14 February 2022.</p> <p>CH asked for any suggestions from Parents in the group for use of slippage monies to be emailed to CH/HB.</p>		Parents
14.	<p>AOB None.</p>		
15.	<p>Date and time of next meeting Thursday 28 April 2022, 11.00am – 1.00pm, via Microsoft Teams</p>		