

Minutes of Parents Advisory Group

**Thursday 24 June 2021
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
 Denise Mountain (DM), Outreach Sister, Royal Derby Hospital
 Amanda Pike (AP), Parent Representative, Lincolnshire & Lincolnshire MVP Chair
 Joanne Leape (JL), Parent Representative, Nottingham
 Sally-Ann Simpson (SS) FaB Worker, ULHT
 Becky Bennett (BB), Parent Representative, Nottingham
 Mikila Round (MR), Family Care Sister, NUH
 Phillipa Nash (PN), Family Support Deputy Sister, NUH
 Elsie Kumar (EK), Sister, LRI
 Nicola Duane (ND), Nursery Nurse, Lincoln County Hospital
 Julie Versteeg (JV), Family Care Coordinator, Nottingham University Hospitals
 Catherine Johnson (CJ), Staff Nurse, Kettering General Hospital

In Attendance:

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

	Subject	Attachment	Action
1.	Apologies for Absence Claire Gartland, Jo Vickers, Margaret Pratt, Michelle Hardwick, Haley Stocks, Isobel Pollitt, Sarah Jones, Rachel Wright		
2.	Minutes and Actions from The Previous Meeting The minutes were passed as a true record of proceedings.	<u>A</u>	
3.	Matters Arising Production of a leaflet around subsequent pregnancies – LH has spoken to the Maternity Clinical Network who are going to review. LH to contact Jenny Brown as a reminder.		LH
4.	Introduction to FiCare Team Cara Hobby and Haddie Borbely have both now joined the Network team and have lots of enthusiasm and ideas. They will be able to concentrate on progressing the Network parent focussed work.		

	<p>CH/HB are both excited to move forwards with the FiCare agenda. They have been out to some units already, with others visits planned over the next few weeks.</p> <p>LH thanked LJ for being a part of the interview panel.</p>		
<p>5.</p>	<p>COVID-19</p> <p>5.1 Parent Access and Visiting</p> <p>From a Network perspective parent access been pretty good with no major issues. Some of the smaller units are operating a parent rota, decided by parents due to the need to socially distance. From a national point of view there is impetuous at the moment to ensure that parents have 24/7 access, and LH has to report this regularly to the National Team. There is little movement on resuming normal access to the units due to Trust IPC guidance.</p> <p>As the national restrictions are due to be removed on the 19th July, there needs to be some thought regarding access for siblings and other family members.</p> <p>AP had emailed some good ideas to LH after the previous meeting to address sibling involvement. CH explained that as part of initial scoping of roles, the care coordinator role is to look at access. HB been looking at how siblings can be involved and is also looking at undertaking a risk assessment around what the actual risks are of reintroducing sibling and grandparent visiting.</p> <p>CH has been in contact with Chelsie Letts from Bliss to ask for a letter of support around resuming visiting. The BAPM document states that visiting should resume to normal from 19 July, although this message may have been lost. All staff to make IPC teams aware of this.</p> <p>AP suggested something along the lines of a sibling diary on BadgerNet, writing notes, story suggestions. SAS mentioned book that she saw at Boston, written through child's eyes which LH is aware of. HB is compiling a list of sibling books in case they can be purchased and provided.</p> <p>SAS mentioned the possibility of starting sibling scrap books. CH mentioned potential walks around the outside of hospitals for those babies who do not require monitoring and are establishing feeding. JL mentioned sibling packs.</p> <p>PN showed the group an example of a sibling colouring book.</p> <p>AP suggested the possibility of devising a Network sibling book and is happy to help with this.</p>		<p>ALL</p>

<p>5.2 Face Masks</p> <p>As previously discussed, some units are embracing the process of parents taking off masks when providing close proximity cares and when they can maintain distance from other parents and staff.</p> <p>All were reminded all of the clear masks which are available through NHS procurement, or even the possibility of parents wearing visors for periods of direct cares. It was noted that procurement of the clear masks is proving to be very difficult</p> <p>JV looked into purchasing clear masks/visors in NUH which were subsequently given the go ahead by IPC but there are problems procuring.</p> <p>DM asked about parent testing and reported that this is happening twice a week in Derby. LH confirmed it is a national requirement for parents to be offered testing, however this is not mandatory for parents to take up the offer. There have been issues reported with parent uptake of testing across the Network.</p> <p>CH wondered whether booked 'mask free' time in units where space is limited might be worth consideration. In the meantime, it might be worth staff mentioning to their own IPC teams.</p> <p>LH to discuss issues with access for siblings and families with the Regional IPC team.</p> <p>5.3 Vaccinations</p> <p>Anyone over the age of 18 is now being offered vaccination, which will mean the vast majority of the parent population will be covered and therefore offer some further reassurance for staff.</p> <p>5.4 Parent Testing</p> <p>Some reticence from parents to undertake testing, however it is interesting that the two units in Network who are offering PCR parent testing do not seem to be having any issues with uptake.</p> <p>CH/HB have produced an information leaflet for parents and poster around parent testing, copies of which were shared.</p> <p>LJ liked the poster and thought it provided a clear message. The two documents will go to CGG to be ratified, and will then be circulated to units for use.</p> <p>All to send any comments/suggestions to LSH by Thursday 01 July 2021, these can then be considered/incorporated and then presented to the Clinical Governance Group to be ratified on 07 July 2021.</p>		<p>ALL</p> <p>LH</p>
-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	--	------------------------------------

<p>6.</p>	<p>Patient and Public Involvement (PPI)</p> <p>6.1 Neonatal Voices</p> <p>All regions have a Maternity Voices Partnership (MVP). Lincolnshire has a neonatal subgroup (NVP). The Network Team continue to work with each of the LMNSs to replicate the Lincolnshire model for NVPs across the region so that in turn they can feed current information into this group. CH and HB will be focussing on implementing these groups as part of their role.</p> <p>LH has emailed each of the LMNSs to get relevant contacts. They will then be invited to attend an engagement event. CH/HB will be assisting in organising this.</p> <p>6.2 Parent Representation at PAG</p> <p>There are more parents attending the meetings which is really positive. All to continue to encourage parents to get involved. CH/HB will also be promoting the group and are working to encourage minority group voices to be heard.</p> <p>Talked previously about having a parent story to be shared at the EMNODN Clinical Forum which would be a great way of ensuring clinical staff hear parent voices.</p> <p>JL has spoken to lots of dads when on the units, and reported that they feel pushed aside generally. There are dads that want to get involved but feel that these meetings are more mum focussed. It was discussed that implementing something which is just for dads would be a good idea.</p> <p>EK reported that she has always struggled in UHL to get parent representation, and is very keen that CH/HB help in getting better parent engagement.</p> <p>MR highlighted the work of Liz Crathern, University of Sheffield around involving dads and what support they need on the neonatal journey.</p> <p>AP mentioned Natalie Whyte the MVP chair in UHL who is keen to get involved.</p>		
<p>7.</p>	<p>Family Integrated Care (FiCare) Project Update</p> <p>7.1 Proposed Plans</p> <p>With regard to working with the units CH and HB have agreed to split the units with CH covering the North hub units and HB covering the South. They are hoping to meet with the link nurses when they are all in place and to support units with recruitment where needed. They will be engaging with the link nurses and will be devising a plan for all to be working towards.</p> <p>7.2 Link Nurses</p> <p>LH will be meeting with finance tomorrow, and is hoping to</p>		

	<p>extend link nurses for longer. Ultimately, we would expect that FiCare will be integrated into everyday practice on all the unit s removing the need for the link nurses. LH will let units know ASAP.</p> <p>7.3 Steering Group There are plans to introduce a FiCare Steering group and those who are interested will be invited to attend. This will include FiCare link nurses, Ward Managers, Medical Leads and parents.</p> <p>CH mentioned the usage of the branding ‘Family matters’ for all the FiCare project work.</p> <p>7.4 BAPM FiCare – A Framework for Practice CH asked for feedback from the group and she will feedback to regional team.</p>		<p>LH</p> <p>ALL</p>
8.	<p>Bliss Update 8.1 Charter Audit & Accreditation Update The Network have provide the funding for all units to get to gold accreditation. Bliss/CH/HB will be working with units to achieve their accreditation.</p> <p>NUH have the only two accredited units in Network.</p> <p>8.2 Locked Out Report A copy of the report was circulated for information which illustrates the impact of COVID-19 on parents. Hopefully this will help with conversations with IPC teams.</p> <p>HB reported that there is a free webinar on 13 June to discuss the report.</p>		
9.	<p>Outreach Update and Proposals for 7/7 The Outreach teams are in place in each of the units or are just about to be implemented. Parent feedback for the outreach service is very good. However, at the moment there is not a 7-day service which impacts upon discharge dates and overall Network capacity. LH, Lucy Panesar and Claire Inglis have written a business case for a 7-day service and have submitted it to Specialised Commissioning to try to secure some funding to extend the service.</p>		
10.	<p>Pre Term Birth Group 10.1 Extreme Preterm Parent Information Leaflet circulated for comment.</p> <p>LJ liked the infographics.</p> <p>BB commented on the whole really good, only comments around severe disability, specialist school. ADHD and ASD.</p>		

	<p>JL mentioned the shock of the look of her baby, skin colour, eyes etc and the group agreed that there should maybe be more mention in the leaflet around what an extremely preterm infant would look like</p> <p>DM wondered if this would be terrifying to give to parents and wondered if the positive rather than negative should be concentrated on. She reported that the Medical staff at Derby were not keen on sharing this kind of information with parents at such an early stage.</p> <p>LH explained the leaflet is only to be given to parents after thorough counselling by the obstetric/neonatal teams.</p> <p>The parents all agreed that this is information that they would have liked to have received.</p> <p>AP talked about photo lighting to ensure that parents receive good photographs.</p> <p>10.2 Transfer Information Parent Information Leaflet circulated for comment.</p> <p>AP to share with NVP for comment.</p> <p>Comments to be back with the Network team within a week, which can then be considered/incorporated and presented to the Clinical Governance Group for ratification 07 July 2021.</p>		ALL
11.	<p>National Feedback</p> <p>11.1 Neonatal Critical Care Transformation Review Update</p> <p>A review of neonatal services was undertaken a couple of years ago, with a report published in December 2019. There was an expectation that all Networks would review capacity, staffing and parent involvement. The Network produced a report and identified that there is a lack of critical care capacity in the two lead centres: Nottingham and Leicester. As a result, there is a regional East Midlands Neonatal Capacity Oversight Group to address the issues which is feeding up to the National Team.</p> <p>The group meets every month in order to maintain momentum and to ensure that the new units are built in UHL and NUH.</p> <p>Building work already started in UHL. Plans are being created in NUH to move all critical care activity to the QMC site.</p> <p>LH feels that the Network is now further forward in terms of overall capacity which is really positive.</p> <p>The National team have allocated funding for nurse staffing in both NUH and UHL. Nationally the money available was a relatively small amount and there will be more available next</p>		

	<p>year which will be allocated according to need. The East Midlands were also allocated a further 290 k and the team along with the commissioners are in the process of deciding what this money will be used for. 70k will be put towards the Network Education Team which will allow the Network to provide a Foundation course for all the new staff so they can prepare for QIS training. There is a meeting planned to decide how the remaining 220k is allocated.</p>		
<p>12.</p>	<p>Local Group Updates & Feedback Derby</p> <p>The BURPs group is still not running, and has not really taken off online. Parents are getting support from parent partnership.</p> <p>Parent access is not limited, however once they are on the unit they are not allowed to leave.</p> <p>New outreach nurses will be starting on 05 July 2021.</p> <p>The Unit sister will be retiring later this year.</p> <p>UHL</p> <p>Parent access is unlimited. Siblings are still not allowed to visit and the unit are keen to work on this.</p> <p>If a family tests positive for COVID-19, there are iPads to enable FaceTime, and they are able to nominate another family member to visit in their absence.</p> <p>The unit have not started Lateral Flow Tests for parents yet.</p> <p>Adapt coffee mornings are not taking place but the team are around and supporting families.</p> <p>FiCare Link nurses; Hazil Turrill LGH, Hema Parmar LRI</p> <p>ULHT</p> <p>Fiona the FiCare Link Nurse has done a really good job with introducing the FiCare folders. A new admission to discharge booklet has been produced and was well received. Visiting is still restricted with a rota for dads because of space.</p> <p>KGH</p> <p>Parents have open access for parents. There are some worries about reintroducing siblings and CJ has contacted Bliss for advice.</p> <p>Swabbing of parents is going quite well.</p> <p>The Community preterm support group is available online but there is nothing specific to report.</p>		

	<p>Use of Badger diaries is in the pipeline.</p> <p>FiCare folders are being worked on.</p> <p>NGH No one present to provide an update</p> <p>NUH The Team are doing vCreate training at the moment. PCR for parent testing is being carried out, and the process is getting easier, with no parents refusing.</p> <p>NUH are working to improve parent feedback. There is a new app out in NUH and the team are trying to get as much feedback as possible and utilising this to make improvements.</p> <p>Working on steps to discharge.</p> <p>Need to look at environment and to improve it after recent feedback</p> <p>KMH No one present to give an update.</p>		
13.	<p>Network Update Funding from LTP for Network AHP team, Physio, OT, SALT, Psychology and Dietician, 0.4WTE for each. Job descriptions have been written and have been submitted for banding. Their responsibility will be to provide leadership, advice and guidance.</p>		
14.	<p>AOB None.</p>		
15.	<p>Date and time of next meeting Thursday 16 September 2021, 11.00am – 1.00pm, via Microsoft Teams</p>		