

Minutes of Parents Advisory Group

**Thursday 16 September 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
Joanne Leape (JL), Parent Representative, Nottingham
Sally-Ann Simpson (SS), FaB Worker, ULHT
Becky Bennett (BB), Parent Representative, Nottingham
Nicola Duane (ND), Nursery Nurse, Lincoln County Hospital
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, Denise Mountain, Anjali Sood, Elsie Kumar, Margaret Pratt, Michelle Hardwick, Sarah Jones, Gemma Manning		
2.	Minutes and Actions from The Previous Meeting The minutes were passed as a true record of proceedings.	A	
3.	Matters Arising LH to speak to Jenny Brown. LH has discussed with JB but will remind her that this is still outstanding. Item to remain on the agenda and LH will update at next meeting		LH
4.	COVID-19 4.1 Parent Access and Visiting CH Asked those present from the units to give an update on the current parent access and visiting situation CJ confirmed that in Kettering parents have 24-hour access which has been the case for some time. Siblings and grandparents are still not allowed to visit, however exceptions have been made to this in a few exceptional circumstances. LH asked what the process is for documenting whether		

	<p>parents are undertaking lateral flow tests, and how results are recorded. CJ to confirm with Mara Tonks and provide and update to LH.</p> <p>ND Confirmed that in Lincoln parents have 24-hour access which has been the case for some time. Siblings and grandparents are still not allowed to visit, and ND is not aware of any conversations to change this practice. Parents are being asked to undertake 2 x weekly lateral flow tests and the uptake is encouraging. Results are recorded in the notes along with whether parents have consented or not consented.</p> <p>LJ asked what the views of parents on the units are in terms of wider visiting. CJ and ND both confirmed that parents are keen for siblings to be able to visit. ND explained that in Lincoln various options are being explored including the identification of a separate visiting room</p> <p>SS said that in general the feeling at ULHT from parents is that although they would love siblings to return, they are very aware of the rationale for the restrictions and understand that they are for the safety of the babies and staff.</p> <p>4.2 Face Masks A link to an article in the BMJ was circulated within the agenda for interest, and highlights the points discussed in previous meetings.</p> <p>CJ confirmed that in Kettering parents can remove their face masks at the cot side.</p> <p>ND confirmed that in Lincoln parents can remove their face masks at the cot side and they are only asked to wear them when moving around the unit. Staff continue to wear face masks at all times.</p> <p>4.3 Parent Testing Covered under item 4.1.</p>		
5.	<p>Patient and Public Involvement (PPI)</p> <p>5.1 Neonatal Voices 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>A regional event is planned for 29 September where Lincolnshire will present their story as a learning opportunity for other regions, and discussion will take place on how to move this forward across the Network</p>		

<p>If anyone has anything, they would like to feature in future editions, CH/HB would love to hear. LJ commented that there may need to be some consideration of the length as this may put people off reading it. CH had planned to circulate it quarterly, but some thought would be given to whether it should be monthly and shorter, to ensure people read it.</p> <p>CJ reported that she had not seen it but will look for it and share with staff, and will send any feedback.</p> <p>SS mentioned the Lincolnshire App. CH asked for a contact to explore the possibility of including the newsletter within the App.</p> <p>HB talked about changes to the website and suggested a newsletter section and QR code as an alternative for an App.</p> <p>CJ explained that Kettering have something called Hot Topics which is a really good format and will forward a copy to CH/HB to look at to see if there are any ideas within it that can be replicated.</p> <p>6.4 Posters New posters were circulated with the agenda.</p> <p>These will go onto the Network boards in each unit and will make parents aware of the PAG and signpost them to it</p> <p>LJ felt that the messaging was not clear in the 'We need your help' poster. HB will review it and aim to make the message clearer. It will then be recirculated for further feedback.</p> <p>CH reported that there will be another poster entitled 'Who are the Network team?' and this will be brought to the next meeting.</p> <p>6.5 NUH Discharge Tool and All About Me CH has been working with the FiCare link in NUH who is keen to get some parent feedback on a number of documents. A copy of the NUH discharge tool and 'All About Me' document were circulated within the agenda. CH asked all to have a look at over next couple of weeks and send any comments to LSH.</p> <p>LJ thought the 'All about me' document was very good visually, and her only concern would be ensuring that it was completed.</p> <p>JL also thought it looked very good and that it would also help with parental anxieties.</p> <p>CH reported that several of the units are working on various discharge tools including a train, caterpillar, giraffe, and</p>		<p>CJ</p> <p>CJ</p> <p>HB</p> <p>ALL</p>
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	<p>octopus.</p> <p>The group felt that the NUH discharge tool was overcomplicated and contained too much information which might cause anxiety and be demoralising for the parents. There was also concern that the bronze, silver and gold sections made it feel like an audit process and could be overwhelming and disheartening. It was also felt that it contained too much medical terminology which would be very off putting for the parents</p> <p>SS reported that she has been working alongside parents using scrapbooks. The parents are taking ownership of these and are even writing journals.</p> <p>6.6 ReCite Me</p> <p>This is a toolbar for the website, which will allow the website to be more accessible and translate the content into over 100 different languages. It is also able to read out loud, and change colours for visual preferences. This also extends to pdf documents.</p> <p>The tool is being trialled for two weeks on a replica website and can be viewed here; https://perinatalnew-stage.azurewebsites.net/ All asked to review, and to share with colleagues and parents. It would be really helpful to get some comments on the quality of translation from anyone who speaks other languages.</p>		ALL
7.	<p>Bliss Update</p> <p>7.1 Charter Audit & Accreditation Update</p> <p>The Network have provided 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 the Network.</p> <p>Chelsie Letts at Bliss has had a baby boy and congratulations were extended. Her replacement has been identified and will be working with the FiCare team on audit/accreditation.</p>		
8.	<p>Outreach Update and Proposals for 7/7</p> <p>The Outreach service is not currently able to provide a 7-day service, which impacts upon discharge dates and overall Network capacity. A business case for a 7-day service was submitted to Specialised Commissioning to try to secure some funding to extend the service. Whilst it has been confirmed that there is no money available this financial year, the importance of extending the service has been recognised.</p>		

<p>9.</p>	<p>Pre Term Birth Group</p> <p>9.1 Extreme Preterm Parent Information</p> <p>The Preterm birth group meets quarterly, and is now well established. The group undertake a case review of each baby which is not born in the right place, to identify any issues and sharing learning.</p> <p>The 'Just say yes' policy for babies less than 27 weeks appears to be going well. At the end of 2020 the data went up to 100% although this has since seen a slight decline, possibly due to COVID-19. This is also the picture across the country, not just within the East Midlands Network.</p> <p>The Extreme Preterm Parent information was amended following comments from this group and has now been circulated to the Clinical & Nursing teams for comment before hopefully being ratified at the October Clinical Governance Group Meeting.</p> <p>9.2 Transfer Information Parent Information</p> <p>Amendments were made and agreed and a copy of the latest information has been uploaded to the Network website. However, this will now need some further amendment following the move of cardiac services from Glenfield to LRI. Information on how to access the unit tours on the website will also be included.</p>		
<p>10.</p>	<p>National Feedback</p> <p>10.1 Neonatal Critical Care Transformation Review Update</p> <p>The East Midlands Capacity oversight group meeting takes place on a monthly basis to review the plans to increase the capacity across the Network, and progress is being made. The NUH Outline Business case has been through Trust Board processes and will be submitted to the Health Overview Scrutiny Committee. The interim plan is for 9 extra critical care cots on the QMC site which will hopefully be delivered by Dec 23. QMC will then be a NICU and City Hospital an LNU. The longer-term plan will be for all neonatal services to be on the QMC site, and this forms part of the 'Tomorrows NUH' plan.</p> <p>In UHL building work has commenced on the new W&C Hospital.</p> <p>LJ asked if there will be any loss of capacity during the works, LH is hopeful that it will not, but this is being monitored at regional level.</p> <p>Money from National Team has been provided to increase nurse staffing in UHL and NUH. Recruitment is underway and The Trusts and ODN regularly report progress to national team.</p>		

	<p>The Network received additional funding for a FiCare team which CH and HB were appointed to, and two education posts which have been offered to the successful candidates and they will start in December 2021. AHP roles have been advertised and interviews will be held in the next few weeks. There are also plans for an additional Deputy Lead Nurse with responsibility for quality improvement and this is due to be advertised shortly.</p> <p>10.2 Care Coordinators Group Update There is a national group, bringing together the Care Coordinators from all of the Neonatal Networks, although some Networks are still in the process of recruiting. The main focus of the meetings so far has been peer support for those already in post. The group has provided a national response to the BAPM FiCare Framework.</p>		
<p>11.</p>	<p>Local Group Updates & Feedback KGH – nothing further to add.</p> <p>LCH – nothing further to add.</p>		
<p>12.</p>	<p>Network Update Recruitment underway as discussed under item 10.1.</p> <p>LH reported that confirmation was received this morning for the development of a new Network website which will be far more interactive for parents and staff. HB will be working on this.</p> <p>There have been capacity issues across the whole of network, mainly due to staff absences, which has impact on Network capacity and as a consequence families are being moved further afield. The teams are trying to ensure that parents have accommodation wherever possible. A letter was produced by the Network team for units to give to parents explaining the need for transfers. The Network Team have been meeting with units on a regular basis, and units are submitting daily reports so that network activity and available cot capacity can be identified.</p> <p>LH thanked the Network team for all their hard work and the progress being made on moving things forward.</p>		
<p>13.</p>	<p>AOB LJ asked for a further update on the previously anticipated, and earlier than usual RSV surges. LH explained that a long flattened curve is likely as we go through winter, but NHSE have asked to prepare for up 100% increase in cases compared to normal years. The Palivizumab vaccination programme has been bought forward and extended to 7 months through the winter months and is already underway</p>		

14.	Date and time of next meeting Thursday 16 December 2021, 11.00am – 1.00pm, via Microsoft Teams		
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