

Minutes of Parents Advisory Group

Thursday 28 April 2022
11.00am – 1.00pm

Via Microsoft Teams

Present:

Lynsey Jones (LJ), Parent Representative, Nottingham (Chair)
Linda Hunn (LH), Director/Lead Nurse, EMNODN
Julie Versteeg (JV), Family Care Coordinator, Nottingham University Hospitals
Phillippa Nash (PN), Family Support Deputy Sister, Nottingham University Hospitals
Nicola Hay (NH), Parent Representative, Nottingham
Sally-Ann Simpson (SS), FaB Worker, United Lincolnshire Hospitals
Denise Mountain (DM), Outreach Sister, University Hospitals of Derby & Burton
Tilly Pillary (TP), Consultant, University Hospitals of Leicester
Becky Bennett (BB), Parent Representative, Nottingham
Sue Flaherty (SF), Discharge & Family Care Coordinator, University Hospitals of Leicester
Nichola Duane (ND), Nursery Nurse, Lincoln County Hospital

In Attendance:

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

	Subject	Attachment	Action
1.	Apologies for Absence Cara Hobby, Haddie Borbely, Gemma Manning, Mikila Round, Joanne Leape		
2.	Minutes and Actions from The Previous Meeting The minutes were passed as a true record of proceedings.	A	
3.	Matters Arising Pick up with Cara the 'all about me' action JV confirmed not much has happened as there has been no office time due to most staff being pulled to work clinically. There were no suggestions received around the use of the slippage money. LH confirmed there have been funds allocated to FiCare for breast pumps, reclining chairs, developmental care aid etc, this is all in the process of being purchased. WC has also contacted units to ask about warming cabinets		LH

<p>4.</p>	<p>COVID-19</p> <p>4.1 Parent Access and Visiting</p> <p>Parents do have access to our units 24/7, and the Network team are asking specifically around this at the peer reviews. More recently Bliss have sent out a recommendation around reintroducing siblings and grandparents, and they won't be progressing Bliss charter accreditations until this is the case. Circulated to units along with an open letter, and pleased to report KMH have reintroduced, albeit in time slots. CH requested meeting with Head of Midwifery and Deputy Chief Nurse at ULHT with possibility of them following suit. The NUH Chief Nurse has also fed back that they are looking at this too.</p> <p>DM reported that in Derby this has moved on and that grandparents/family/friends can now visit, still only two allowed at any time by the cot side and only siblings over the age of 12.</p> <p>4.2 Parent Testing</p> <p>There is no longer an obligation for parents to test, some units are continuing but this is not consistent and as tests are no longer free to the public it is not something that can be insisted upon. Masks are continuing. This will be picked up in the peer review visits to get a really clear picture of the current situation.</p>		
<p>5.</p>	<p>Patient and Public Involvement (PPI)</p> <p>5.1 Neonatal Voices</p> <p>Updates from established NVPS:</p> <p>Fantastic work from Lincolnshire NVP looking at how to support military families – this is the animation they created that explains who they are, why they are needed and what their aim is: https://youtu.be/Mg7OmiLSrLo</p> <p>Derbyshire NVP is gaining momentum and have been working on a coproduced project to create baby tags for prams/car seats/travel systems etc. They have also created new promotional material.</p> <p>Work continues with Leicestershire, Nottinghamshire and Northamptonshire to get their NVPs up and running</p> <p>Network coproduction project in the pipeline: a focus/engagement event to discuss FIC experiences by medical staff and look at planning content for a FIC training package aimed at medics</p>		

<p>6.</p>	<p>Family Integrated Care (FiCare) Project Update</p> <p>6.1 Link Nurses Link nurse funding to continue for additional 12 months. There are some vacancies across the region. New recruitment process will require potential candidates to submit an expression of interest and have an informal discussion with Network and parent representative to ensure right for role.</p> <p>6.2 Steering Group Update Due to sickness the last meeting was a shortened one. Meeting are currently looking at parent ‘competencies’. These are not well used and the group are seeking to understand why so that improvements can be made. Common feedback from staff is that they are too onerous and a duplication of other work. Common feedback from parents is the concept is patronising e.g. having to prove can care for baby before able to do it – wouldn’t have this approach if not a neonatal patient.</p> <p>6.3 Surveys surveys are currently open at all units to ascertain staff personal thoughts and beliefs about FiCare – this will help us read the culture and address any changes that are needed. February was ‘Feedback February’ – using SmartSurvey we collected 30 responses from families within the community who had experienced neonatal care and 43 responses from inpatient families across the region, this survey was about family experiences pertinent to FiCare. In the process of analysing data to create a report.</p> <p>6.4 Leaflet Translation Update Network have opened an account with AA global and sent the first leaflet for translation into the top 5 languages across the region (Romanian, Polish, Gujarati, Lithuanian, Urdu). First leaflet to be translated will be the parent information transfer leaflet.</p> <p>6.5 FiCare App TP explained that the App for the local population, largely in video format, with QR codes and will be accessible across different languages and therefore address some of the current inequalities in the care that we provide.</p> <p>Need parent representatives to co-produce.</p> <p>Whilst aimed at parents it will be a resource that medical staff can use too.</p> <p>Have funding from LLR region to do the work and create the App. The pace will be determined by the setting of the subcategories, and when parent representatives are on board to help coproduce.</p>		
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	<p>6.6 Family Matters Social Media Social media strategy has been drafted and the lengthy process of content planning is underway for the various platforms. Aim is to be engaging, informative and educational aimed at both family and staff.</p>		
7.	<p>Bliss Update 7.1 Charter Audit & Accreditation Update There was lots of discussion at the last PAG around the accreditation scheme and ‘bronze, silver, gold’ terminology which CH fed back to Bliss who have sent the following response:</p> <p><i>“That’s really insightful feedback – thank you for sharing with me. The stages within the Baby Charter are there to encourage units to regularly take stock of their practice, and identify spaces for development or improvement. A unit that has achieved Bronze might already be delivering excellent levels of Family Centred Care, but we recognise that this is ever-evolving and the Baby Charter helps units to look at their progress and identify where they may need to make changes. As part of the auditing process, we often ask for more information or provide recommendations, which units are easily able to complete. Even once a unit has achieved ‘Gold’, we still contact them annually for an update across the three-years of an accreditation, before we then re-assess for their accreditation to continue. The Baby Charter is therefore able to ensure that units are providing a consistent level of Family Centred Care, as well as a high level of it.”</i></p> <p>After further discussion with Holly about this she informed me that they have in their financial year 22/23 plans to review all of the Baby Charter webpages (in collaboration with parents and HCPs) to reflect some of the thoughts we discussed. The feedback from this group has been noted and will be included in any updates and they are going to add a new sentence or two to the current webpage to explain more clearly.</p>		
8.	<p>Unicef Update The Network has funded train the trainer course for neonatal standards and offered places to each unit across the Network.</p>		
9.	<p>Outreach Update and Proposals for 7/7 Business case for a 7-day outreach service, including home phototherapy has been submitted to specialised commissioning, there is currently no decision on this.</p>		
10.	<p>Pre Term Birth Group Been a really positive innovation between the Network and the Maternity Clinical Network. All extreme preterm babies not born in a NICU are now being reviewed to find out if there was missed opportunity to move them to a NICU. Any learning is</p>		

	<p>shared within the group. Q3 there were several babies not moved, but actually only 2 of these could have been moved, which is really positive.</p> <p>10.1 Extreme Preterm Parent Information Went to Clinical Governance Group yesterday for review and will be uploaded and available on the Network website shortly.</p>		
<p>11.</p>	<p>National Feedback 11.1 Ockenden The Ockenden report has been produced after failings in care at Shrewsbury & Telford Hospital. The Network were asked by specialised commissioning to produce a response to the report. A few Network actions have been identified around pathways and looking more closely at our exceptions. All of this work is underway and will be monitored through the Board.</p> <p>Derby now takes from 26 weeks. Burton now takes from 32 weeks.</p>		
<p>12.</p>	<p>National Feedback 12.1 Neonatal Critical Care Transformation Review Update Work is underway nationally around the critical care review. In the East Midlands it's about creating enough capacity in NUH and UHL. There is an East Midlands Neonatal Capacity Group (EMNCOG) which meets monthly to try to maintain momentum. NUH have an interim business plan for additional cots on QMC side. Long term there is 'Tomorrows NUH' where all Maternity and Neonatal Services will be on the QMC site.</p> <p>UHL were successful in securing funding from government to build a new Womens & Children's Hospital on the LRI site. However, the date has been pushed back now until 2027 which sits outside of the timescales for delivery of the neonatal critical care review. The short-term plan is to open additional cots on the LRI site, and they are in the process of recruiting in order to staff these additional cots.</p> <p>Staffing money was allocated by the national team to NUH, UHL and RDH and recruitment is now underway.</p> <p>AHP & medical staffing there is no national money for these posts, there are significant gaps across the Network, and these are being checked in the peer reviews. Have highlighted to units that there is no national funding and so this will need to be highlighted through their LMNS and then onto ICSs.</p> <p>Have recruited our Network AHPS posts: OT, Dietitian, Psychologist, Physiotherapist</p>		

	<p>12.2 Care Coordinators Group Update</p> <p>The national care coordinators group focus is currently on reinstating family (siblings & grandparents) visiting to neonatal units. Many other Networks are ahead of us in terms of progress with this. Jacinta Cordwell's data presented to Network managers group.</p> <p>The cot side visits have started with Burton already complete. Collected some really good feedback which will be utilised going forward.</p>		
13.	<p>Local Group Updates & Feedback</p> <p>ND – visiting is just parents. Are asking IPC daily about siblings and grandparents.</p> <p>SAS, there have been exceptions made in exceptional circumstances.</p> <p>RDH – lots of changes in staff. Recently recruited 2 x band 7; a Bereavement Nurse and an Educator.</p> <p>A little stuck with outreach as there is no Band 7 in post at the moment. Asked for support from medical staff and Matron to try and push forward.</p> <p>Still not been able to reinstate BURPs group.</p> <p>The breastfeeding room has just been revamped and was funded by the Friends of the Baby Group.</p> <p>IN NUH the family group is going through some changes, and hoping to restart in June however, will still be looking at wearing masks and social distancing. Will report back at the next meeting how this is going.</p> <p>There will be a revamp of the parent room at City Campus with the donations from a family who lost a baby.</p> <p>Visiting not changed as yet but signs are promising.</p> <p>A new Rainbows nurse has started at NUH.</p> <p>Coffee morning up and running but uptake hasn't been great.</p> <p>New SLT in post and just finding their feet.</p> <p>A Neonatal Ball is planned for September and has been advertised on the NUH Neonatal Facebook page.</p>		

14.	<p>Network Update</p> <p>There has been lots of recruitment of late. Wendy Copson has joined as Deputy Lead Nurse for Quality & Service Improvement and is making great strides already.</p> <p>The neonatal unit peer reviews are underway.</p> <p>The Network have been allowed to roll over the underspend money into next year and a spending plan has been devised against this.</p>		
15.	<p>AOB</p> <p>SAS talked about lots of parents with financial issues, trouble getting to hospital and asked for any signposting suggestions to get in touch. LH signpost to Family Fund, there are also some useful links on our website.</p> <p>There are wellbeing links in Lincoln who provide a worker to help families; looking at finances; petrol, food etc.</p>		
16.	<p>Date and time of next meeting</p> <p>Thursday 21 July 2022, 11.00am – 1.00pm, via Microsoft Teams</p>		