

**LLR NVP Committee Meeting**  
**Minutes of Meeting held on 16<sup>th</sup> October 2024 at 10am**  
**Via Zoom**

| <b>Present (members):</b>      |                                                  |
|--------------------------------|--------------------------------------------------|
| Nafeesah Tutla (NT)            | MNVP Co-Lead                                     |
| Anita Gondal (AG)              | Leicester Mammals MNVP Coordinator               |
| Katie Simpson (KS)             | Parent Representative                            |
| Hollie Hughes (HH)             | HealthWatch Rutland                              |
| Zaheena Zaffaron (ZZ)          | Parent Representative                            |
| Mumtaz Rehman (MR)             | Parent Representative and Subcommittee Member    |
| Jess Smith (JS)                | Stork Nurse                                      |
| Emma Barnett (EB)              | Parent Representative                            |
| Sophie Kanabar (SK)            | HealthWatch Leicester and Leicestershire         |
| Leanne Marsden (LM)            | Doula and Parent Representative                  |
| Prab Sagoo (PS)                | Parent Representative                            |
| Dr Emma Hoogerwerf (EH)        | NN Psychologist                                  |
| Emily (E)                      | Trainee Psychologist                             |
| Sam Robinson (SR)              | Nurse and Parent Representative                  |
| Aatiqah Shaikh Blackburn (ASB) | Parent Representative                            |
| Khalood Zaffaron (KZ)          | Parent Representative                            |
| Tilly Pillay (TP)              | Head of Service, Neonatology                     |
| Katrina Bisby (KB)             | Clinical Specialist Physiotherapist, Neonatology |
| Goodness Wilson (GW)           | Parent Representative                            |
| <b>Apologies:</b>              |                                                  |
| Jess Parkins (JP)              | Doula                                            |
| Salma Kidy (SK)                | Patient and Community Engagement Officer         |
| Beatriz Rengifo (BR)           | Parent Representative                            |
|                                |                                                  |

| ITEM      | SUBJECT                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   | ACTION |
|-----------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------|
| <b>1</b>  | <b>Welcome, Introductions &amp; Apologies</b><br>All members introduced themselves. Apologies were noted as above.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |        |
| <b>2.</b> | <b>Minutes of the last meeting and Matters Arising</b><br>a) The notes of the meeting held on 05.06.23 were agreed as a correct record<br>b) Matters arising:-<br>None<br><u>All other actions were marked as completed or on the agenda.</u>                                                                                                                                                                                                                                                                                                                                                                                                                                                             |        |
| <b>3.</b> | <b>Update on Current Areas of Focus</b><br>NT gave update on areas of work.<br>The MNVP has been asked by UHL on ideas for décor for the Neonatal (NN) unit. Asked for NN parents' suggestions. The hope is to make an otherwise quite clinical environment warmer and more inviting. NT has discussed with some NN parents in the last week from ideas seen online. One article NT spoke about how they had grown up NN children to create artwork to be displayed around the unit. This would be donated artwork by parents displayed appropriately in frames on walls. Wanted to open out to everyone so everyone has a say on what would make you feel comfortable.<br>MR: <b>An underwater theme</b> |        |

TP: We know we need to make changes to the service-must be more welcoming. Is it too bland and clinical at the moment? Do we need to change? If we need to change, how do we make it culturally sensitive to all populations?. We haven't been too aggressive with the decor so far, as it is a sombre environment, and don't want it to be too much associated with one cultural group. We want to ensure any change is appropriate to all cultures. Some people get sidelined by accident because we don't speak their language.

Comment in chat from LM: [The 15 steps will help this I feel?](#)

NT: We had a discussion around this as we were going around as we know it's something we needed to look at while we were in the environment. There has been some effort that had been put into the artwork and décor and a bit of thought already, but it needs updating. There were some really good aspects-photos of babies on discharge for example.

We had a woodland theme discussion and how Leicester is known for foxes. But conscious there was only 4 of us, and it should be open to everyone.

What are everyone's' thoughts on the suggested ideas? Can take it away and send in thoughts later too.

Question in chat from LM: [Do we have images/videos to share so we know what changes might be suggested?](#)

Comment in chat from KZ: [My thought is having health care professionals wearing colourful bright scrubs to make children interact on rather than a plain uniform.](#)

KB: We are really trying to gather ideas and thoughts around it, we are gathering Health Professionals ideas too, and hope to come up with best ideas. Ideas from everyone and not led by one group. The aim is for a hopeful and calming environment. Pillows for example, and making it an accessible environment so that parents can care for their baby without having to ask. Hoping to encourage parents to be there more for their babies. If we had a sea theme, could have shells with babies name on for example. Not totally unclinical, but somewhere that people want to be. Thinking of things we might not have thought of, from a parent perspective. From a uniform point of view, unfortunately can't have lots of different colours as different department have specifically coloured uniform.

JS: From working in ITU, the most overstimulating thing for parents is noise from machines, so whatever theme we go for, it has to be calming. Theme doesn't have to be overwhelming.

EH: A suggestion I heard from another member of staff was to have a black and white theme to support neurodevelopment. Probably not something they could have everywhere, but perhaps black and white artwork.

KB: There is a difficulty with overstimulation. We are trying to read babies cues of when they are ready to participate. If everywhere is stimulating for them, they are forced to participate.

Comment in chat from LM: I think knowing what it looks like now, have some suggestions and put it out to the community?

NT: There is a video. NNU tour being created of the unit, so that might help, or if there are some images KB could share, we could then circulate those.

Comments in chat :

LM: Need to consider other senses too?

Colours that are proven to be calming are yellow, teal?

JS: I think the art work from previous patients is a lovely idea, especially if we could have a plaque below each picture with the artists name and how preterm they were born? I think that definitely has a place in the unit somewhere.

KB: The other suggestion for colour is lilac as this is the NN colour. We could incorporate this. Give ideas to NT who will feed in through us, and we'll come back with some ideas.

EH: *Showed us the 'Interview Room' she was in. Light green walls, one wall with some décor on, and some sofas.*

NT: We discussed at the 15 steps that it might be an idea to change the name of the room, as it could sound a bit off-putting to parents.

Comment in chat from LM: I love lilac, though lots of trusts use lilac as their space following stillbirth.

NT: That's a really important point to consider. And butterflies can have that association.

Comment in chat from GW: A calming and yet colourful environment would be nice the colourful obviously won't be everywhere but a specific spot.

SK: Definitely at least one wall with warm colours, perhaps soft music (although) we need to be cultural aware. Smell is also important

NT: Music might be an issue as have to keep volume low for babies on NNU.

MR: Purple is also for breastfeeding, and also a medical condition I have which is not fun. No matter what will have some overlapping things. No matter what, people will associate, so maybe variety of colours better.

PS: Agree with others about calmness, and too much colour is overstimulating. Don't want too much in your face, it needs to be relaxing. I think there should be a more comfortable sitting area for parents if you're

breastfeeding. They do have an area, but not as comfortable if you're sitting there multiple hours a day. Not enough pillows. Comfort for the mum more so than colours on the wall.

We stayed in the parent room for 2 nights. It was a godsend we could stay, but the bed was horrendous. My back was hurting. We were told the beds were donated a few years ago.

KB: I agree about the bed. I share your pain. Pillows going to be sorted quickly. Parents beds not on the agenda yet, but I will make sure they stay on the agenda so can get things changed.

PS: One other thing I wanted to mention was staff wearing perfume. I was on crutches and in a wheelchair. My senses were overly heightened. The heating in the unit was on in June. Felt quite nauseous, and difficult to be comfortable.

JS: This is something that we don't realise as nurses. Nurse also find it difficult in the heat. We can put out a comms about wearing subtle scents. But then there is the risk that the smell will be BO.

KB: It is difficult, but we also need to consider the babies. If there are lots of overwhelming scents that can prevent bonding.

JS: What is recommended-BO can also be overpowering?

KB: There isn't a recommendation in this situation-it's a difficult balance-neutral scents may be the best option.

PS: One final thing I wanted to mention; I can't remember her name but she wore a green uniform. She did a hand/foot print of my baby and give us a bag of stimulating toys. It was really touching and meant a lot to us. Made feel really welcome. Really amazing to have.

Comment in chat from GW: [Wow that was a great experience Prab. i would also suggest that volunteers are trained who could go in and interact with mum and obviously answer some well being questions they have.](#) 🗨️

MR: It was mentioned about using black and white. Vision for babies isn't great, so maybe mobiles?

NT: There are a couple of further updates. The first 15 steps was held at the LRI on Sunday. Would like to take the opportunity to thank those who attended and Chelsea who was really inviting and open. We will create report and share after the next 15 steps at the LGH next Sunday. Also, we have previously heard feedback from Neonatal parents about the need to address mental health support once babies have been discharged home. It can be quite overwhelming as whilst on the unit parents have expressed that their focus is on the baby, often centred around the needs of baby and they have not had time to really think about what has happened. Once home, they have a chance to reflect on what has occurred

|    |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |                                              |
|----|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------|
|    | <p>which can be a lot for parents to take in. We are aware there should be more support for parents around this. We will keep members updated on this.</p> <p>PS: Is there any chance if parent rooms are not in use, of an overnight stay so staff are nearby?</p> <p>JS: It's a lovely idea, but the chance of rooms not being used is very low. Perhaps when we have the new unit, this would be a possibility.</p> <p>TP: One thing we have to do is figure how to get more parents to room in. We were talking about cross sharing beds at the units, especially for parents from out of area. So if for example there is no bed at the LRI, but there is at the LGH, they could stay at LGH and take the Hopper bus. If we are lucky enough to see the new unit, we will have majority single rooms with beds. We don't expect parents to stay every day, but if we get this, it will be an opportunity for parents to stay whenever they want.</p> <p>NT: Last update. It is lovely to hear that free meals for parents on the Neonatal Unit are now in place. Now just waiting for free car parking for Neonatal Parents which we look forward to Tilly updating us on. Thank you.</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |                                              |
| 4. | <p><b>UHL Neonatal Update (TP)</b></p> <p>We are now able to offer free parking for one parent. We are currently arguing for provision for divorced/separated parents. There was a misunderstanding that it was only for breastfeeding parents. But it is for all. Cold food vouchers are now in place. For the hot food, we are just working out how to get the food trolley downstairs and manage the logistics of everything.</p> <p>The lady in the green uniform that was mentioned is our play therapist. We had two employed but one recently passed away. She is called Fay. Her job is to make sure parents feel loved, wanted and engaged. Will be thinking about replacing the lady we sadly lost, but this will take time</p> <p>We have now completed a Gap Analysis for the Allied Health Professionals (AHP) on the unit. We need 13.5 more full time equivalent roles. This is very big job to fill these gaps. The business case is being worked up but it is a long process. This is a priority.</p> <p>We might want to advertise, but we also need people around who are trained to support people new to the role. Other trusts are also recruiting. We have to be careful we don't lose who we have already, so it's a very big piece of work.</p> <p>In terms of the point before, around mental health support, it's always useful to raise this when we have meetings. It is important to raise the need for mental health support.</p> <p>I will send a Mentee-meter poll to NT with regards to the programme we offer: Stork. One of the things we've shared previously is that the highest risk for babies dying is in the newborn period. Deaths in first year of life is an indicator of the health of the nation. In our region and the UK, there are a number of risk factors such as not breastfeeding, smoking, being preterm, not understanding when to get baby into hospital, not knowing protective factors. We want to understand how to get it better and deliver it better. Where to deliver-antenatal, postnatal, HV, and how to scale across</p> | <p><b>TP to share STORK poll with NT</b></p> |

the country. Now have people from universities across the country working with us and going to grant application to do this. It will be studied across multiple regions.

At the Stork Stakeholder meeting, stakeholders from across the region recognised it was important to take forward, and liked the digital programme to do this. The digital team said let's ask families what are the most important risks to study. Will send out poll around this. What needs to be measured? Could Leads look at this, and get feedback from members?

Talking about improving services in terms of structure, and décor, but bigger piece of work is also needed around a small working group to map out the parent journey. What would you like to see when you come onto the ward? What information would you like? Leaflets? People to greet and explain things? It is all there in part, but not all right. If you tell us what your ideal parent journey would be and how you are taught about processes and the follow up journey. For those who have already had that experience really helpful to know your thoughts. And helps to address parents who have difficult experiences.

PS: I completely agree with making experience more comfortable and friendly. My experience was that my baby had really low blood sugar. Husband knew straight away, but everyone on the day staff said he was fine. It was only when the night staff came they said it was low. The way it was handled, in terms of not knowing what was going to happen was difficult. I'm a biomedical scientist so quite rational in thinking, but when it's you in that situation, you just go into panic mode. My baby was latched on, and the consultant just unlatched and took him. When Dr left with him, there was no other explanation. I was told you can rest now and see him in the morning. I just broke down. There was no staff member to talk to or ask what was happening. It was the longest 8 hours of my life. I was told when we got to the unit we could have rung for an update but we weren't told this before. No one had asked for an extra set of clothes so he was in soiled clothes. You can't really prepare for something like that, but you could give a bit of a heads up.

We missed so many of the basic firsts, which you just don't get to do-I first changed his nappy at 4 days. When you are discharged home, you haven't done those things and it can feel overwhelming. Which is why I suggested the parents room. Going from a whole week of someone looking after him, to then being expected to look after him alone. Can understand why people struggle. I had PND from the experience. I had no issue with bonding with my baby, but issue was because of the situation. I still have difficulty handing over my baby. Understand its protocol and tick boxes to do job, but just pausing and putting yourself in the other persons situation would make a difference.

NT: thank you for sharing experience. So many valid points others will share.

Comment in chat from PS: [This trumps the whole decorations for me tbh](#)

**Request from TP for a working group to map out NN parent journey.**

|    |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |  |
|----|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--|
|    | <p>NT: Decorations are important in relation to how the environment can make parents feel but there are also other more important aspects to think about, in particular, the support for parents should be there.</p> <p>MR: If the support for Mental Health is about funding, I'd rather not have décor, and have the MH support instead. PS's experience is not isolated. Think this needs to be given much more importance than décor. If my situation had been handled differently, wouldn't have had some of the issues I came out with.</p> <p>TP: This goes back to my first point about if you want décor. Problem is the funding comes from different pots. So have to think imaginatively about how we do this. Posts are a commissioned process with money from the government. I'm so sorry to hear about these experiences. It's really humbling.<br/>Please reach out for support</p> <p>Comment in chat from LM: I do worry that this is the norm and not the exception. As a doula I see so much of this type of lack of communication and lack of empathy. I'd hope it would be better in neonatal and I've had clients that have been so positive about the care but I also genuinely understand what you're feeling.</p> <p>Comment in chat from PS: After that first interaction, I have to say my stay at nicu was amazing. The staff were so attentive and supportive</p> <p>Comment in chat from MR: Just to clarify what I meant regarding my input.. I wouldn't want to take away from one area and give to another, it was just an example of the importance I feel needs to be given to the mental wellbeing of parents and their babies.<br/>My stance is always clear on this, that once a baby has been in nicu/scbu, that parents should automatically qualify for counselling</p> |  |
| 5. | <p><b>Transitional Care</b></p> <p>NT: Met Dr Jo Preece at LGH and discussed the transitional care process. Babies who are born between 34-35+6 weeks or a specific weight, who may need extra care, but not on the NN unit. Aim is to keep them on the postnatal ward to reduce separation of mother and baby. Care to be delivered on the postnatal ward in dedicated bay.<br/>What would parents need to make it a smooth process, and what information would parents need. We discussed food being provided for parents.<br/>What do you feel is needed. Furniture? A welcome pack?</p> <p>TP: When I spoke about parent journey, part of it is having a leaflet, but what actions needs to happen to bring it all together. Think we need to have a couple of parents who have been on that journey and asking what they want/think should happen. Need a parent journey for this too.</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |  |

|    |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |                                                                                                     |
|----|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------|
|    | <p>NT: Am I correct in thinking we don't have a proper pathway for this as well as no-one has gone through it yet?</p> <p>TP: Yes that is correct, but there will have been mums who have been on the ward with babies needing to gain weight.</p> <p>NT: Also about building parents' confidence.</p> <p>Comment in chat from LM: <i>I have plenty of parents I can ask. But I already know many of their experiences</i></p> <p>NT: Some thoughts: a welcome pack, tv screens, food and drink-where and how to store, dayroom facilities, furniture, sockets, what is provided for babies and what parents will need to provide, visiting times, birth partner info, feeding support, info about homecare team, STORK info, who to speak to about yours and your baby's care, possibly staff routines to help with communication and who to speak to if you have concerns..</p> <p>LM: <i>I don't think a welcome pack, but maybe a what to expect when you leave? Sorry, I got you, I just don't know if people will read them as they're overwhelmed?</i></p> <p>NT: Agree it can be overwhelming. Idea that it's there and can be referred to when needed. Information should be accessible for when parents need.</p> | <p><b>Members to share any other suggestions about what is needed around transitional care.</b></p> |
| 6. | <b>Any Other Business;</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |                                                                                                     |
| 7. | <b>Date of next meeting;</b><br><b>12<sup>th</sup> December 2024 @ 7.30pm (Online via Zoom)</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |                                                                                                     |