

LLR NVP Committee Meeting
Minutes of Meeting held on 5th June 2024 at 7.30pm
Via Zoom

Present (members):	
Nafeesah Tutla (NT)	<i>MNVP Co-Lead</i>
Fatimah Panchbhaya (FP)	<i>MNVP Co-Lead</i>
Anita Gondal (AG)	<i>MNVP Co-Lead</i>
Holly Brookes (HB)	<i>Student Midwife</i>
Elaine Boyle (EB)	<i>University of Leicester Researcher: LCFC Professor in Child Health</i>
Ben Baucells (BB)	<i>NNU Consultant</i>
Harriet Leyland (HL)	<i>East Midlands Care Coordinator (FICARE)</i>
Mumtaz Rehman (MR)	<i>Parent Representative</i>
Dulna Shahid (DS)	<i>HealthWatch Leicestershire</i>
Katie Simpson (KS)	<i>Parent Representative</i>
Prab Sagoo (PS)	<i>Parent Representative</i>
Natalie Whyte (NW)	<i>Service User Voice Representative Midlands</i>
Tilly Pillay (TP)	<i>Head of Neonatal Clinical Services UHL</i>
Katrina Bisby (KP)	<i>Clinical Specialist Physiotherapist Neonatal Unit</i>
Tosan (T)	<i>NNU Consultant</i>
Samia Kadri (SK)	<i>Parent Representative</i>
Sanjana (S)	<i>Parent Representative</i>
Apologies:	
Bev Cowlshaw	<i>Specialist Midwife in Public Health</i>
Rabina Ayaz	<i>CYP Senior Officer-Maternity</i>

ITEM	SUBJECT	ACTION
1	Welcome, Introductions & Apologies All members introduced themselves. Apologies were noted as above.	
2.	Minutes of the last meeting and Matters Arising a) The notes of the meeting held on 28.03.24 were agreed as a correct record b) There were no matters arising.	
3.	Current Areas of Focus NT: There has been a lot going on over the last few months. Thanks to MR and SK for attending the STORK Stakeholder event last week. There was lots of great discussion and we are looking forward to hearing about the research. NT attended an 'Adapt' group for Neonatal (NN) parents with HL, where it was great to hear experiences of NN families. We hope to use this feedback to make changes. We are in the process of setting dates for the NN 15 steps at LRI and LGH. We will circulate dates when we have them, and please get in touch if interested in being involved.	NT to circulate 15 steps dates when arranged. Members to get in touch to be involved.

	<p>We have done 15 steps visits previously in maternity and feedback has begun to be taken on board already so this is a great opportunity to get parents voices heard.</p> <p>Some positive updates to share-Feedback previously was that the water cooler was not accessible and this has now been changed. We have shared feedback about cuddle buddies in FiCARE, and this was taken on board. We've shared members feedback with the NN Unit on the Amazon Wishlist that was proposed, and will share an update on that when we have it. TP will be giving an update on car parking and meals for parents on the units later in the meeting.</p>	
<p>4.</p>	<p>TP NN Update Expressed what a pleasure it is to work with the NVP. Working to make things better for NN families one of the most important aspects of our work. Extended thanks from whole NN Unit.</p> <p><u>First Update:</u> Feedback on NN parking-the question has been raised as to why we are the only unit in the region that charge for parking, and why are mothers not fed on the unit. With your support, we have been able to do a piece of work on parent perspective and put a business case to the trust and been given a verbal accord that this will go ahead. Parking will be free for parents using the NN unit, and parents will have meals provided when they have a baby on the unit. We have had a verbal assurance from the highest level, so now will have to wait for the chain down to enact that to work out how all this will work. Will have to look at the budget, but reassured that this will happen because it is also reinforced by the network review. Please remind at every meeting to give update.</p> <p><u>Second update:</u> at the FiCare meeting a few months ago, we asked for opinions on cuddle buddies. There are some units in the country where medical students are used to support families by engaging with baby in lieu of parent. This is a 2 way process-helps baby from developmental point of view, and helps medical students to get confident with babies. We asked the lead from that programme (Cambridge) to talk about it. The NVP perspective is that we must promote parent engagement, rather than promoting cuddle care. May have value where baby is going to foster care or no available family. When we looked at the priority we should focus on, this should be to encourage parents get onto the unit. Free parking and parent led ward rounds will help with this. With Parent Led Ward rounds (PLWR), we are encouraging the team to introduce themselves to parent, then nurse, and then ask parent what they would like to tell us about their baby. Every parent gets a leaflet on PLWR. Get feedback from parents, then start the ward round.</p> <p><u>Third update-Accurx.</u> This is a SM and Texting service. The team are working so we can share key messages with parents through text. E.g. Ward round starting at x; nearest restaurant is, whatever the key messages parents</p>	<p>NVP to check progress of free parking and parent meals each meeting</p>

want to hear about. By doing these things we are encouraging parents to engage and helping them come to the unit to spend time with their baby. Developmental care programme will support engagement with family. Cuddle Buddies put aside and focus is on engaging with parents. Accurx will be a month or so in the making.

Question from PB: [Is the car parking charges only for the neonatal unit, or for all of maternity? Will food only be provided for mothers or fathers too?](#)

TP: At the moment can only speak for the NN service. Maternity service different.

Food is for both according to my perspective, but have to bear with us as we go through the process to put things in place.

Fourth update: Getting families ready for home and getting families involved in care- at the moment this involves a booklet from the network called the competency booklet, looking at NG tubes, bathing etc. Insight from NVP was that by saying 'competency' we imply there is a deficiency, so we will be looking at changing language to something along the lines of 'Acquisition of skills to care for a preterm baby at home'.

Fifth update: STORK programme-Monday's meeting was very useful. Representation from East and West midlands, and the parent voice was strong. We did do STORK training a few years ago with Leicester Mamas and the idea is that over time we engage with the 3rd sector and get them on board with engaging with parents.

Sixth update: Amazon Wishlist-KB and RM asked your thoughts on this. Took feedback back that you liked the idea of a Wishlist but not just Amazon-not associated with one brand. We will create a Wishlist with a QR code that can be adjusted according to requirements. This came about because people want to give, but we need to be able to tailor it to what we want. Will put together a list and run it past ward managers and look at how to log gifts and it will be circulated broadly without any pressure.

We wanted a display board in the parent area that gave parents a perspective on what's in the local area. Sometimes parents come to the unit from far away and don't know the local area. Information on facilities, how to navigate local area etc. We will be looking in to that.

15 steps-anxiously awaiting feedback so we can start developing area to make it more homely and friendly. Wanted to invite a member to explore a nearby family unit that has done FiCare well. No date yet, but if we have a volunteer we can work with them on when is convenient.

Next request is around consistency of messaging. Feedback is that the team are good at doing what they do, but sometimes there are lots of messages, but the messages are inconsistent. This is a big team who rotate, so it's unlikely to be the same consultant there all the time. So the question is what do you need in terms of consistency of messaging and how can we develop structure that will ensure consistency of messaging?

Volunteer from NVP needed to visit nearby family unit. Members to get in touch if interested

NVP to get feedback on consistency of messages

TP to email NVP

	<p>Will write in an email so it is easy to disseminate to members.</p> <p>NT-We can ask members and look forward to getting the 15 steps dates.</p> <p>FP Thanks for update and great to hear lots of positives.</p> <p>PS: <i>In terms of parents being involved with morning rounds, do staff have time to do this before the Ward Round?</i></p> <p>TP: yes absolutely. This is now the standard of care. We don't always know the time it will start due to emergencies etc. but every parent on the ward should be given to tell the team about their baby and have chance to ask questions and share concerns.</p> <p>PS: <i>I remember when we were there, there were 16 babies and they were pushed for time so didn't see how they could, but things may have changed now.</i></p> <p>TP: Staffing fluctuates, but the ethos is that the team has to make time for the parents. Parents feel more engaged and involved. We have started audit and this has been really positive in terms of how involved they feel. May be some days when the ward is so busy they have to speed through, but this must be a rare occasion.</p>	<p>TP to send over suggested 15 steps dates</p>
<p>5.</p>	<p>Research Project Information: EB</p> <p><i>EB shared slides in her presentation which will be circulated alongside the minutes.</i></p> <p>Thank you for inviting me. Any research we do means nothing if it means nothing to parents and families. We need to ensure you feel it is important and you can guide us and make sure we're going about it in the right way. EB shared a number of slides to illustrate what exactly the research is. It came about from a donation of £1m from LCFC to UoL. The only remit is that it is to be used for high quality research to improve outcomes for children. We devised a series of studies about how early life experiences affect development.</p> <p>The hope is that this programme will help develop future leaders in this area. Why have we chosen to do the research this way? We know from child health data that compared to national data there are a couple of areas that stand out as needing work, such as pregnancy, low birth weights, and mortality. Leicester has increased rates of childhood obesity, poorer school readiness, higher early years A&E visits. There is also lots of child poverty. Lots of work to do. We can't do it all immediately, but we can make a start.</p> <p>There are a huge number of factors that influence child health, some which are particular to Leicester, such as the ethnic mix and poverty. Some are obvious areas for improvement and we are looking at lots of these areas. The research focuses on babies born between 2 and 6 weeks before their due date. Most previous research has focused on very premature babies, because they are the sickest and most likely to have poor outcomes. About 8000 babies in UK are born severely premature. For late premature babies it is more like 200,000. There are a substantial number in Leicester. Even babies born 2-4 weeks early are likely to have problems, and it's becoming</p>	

clearer through research, but these problems are much less severe. And many don't go on to have problems later. What we don't know is why some babies don't do as well as other. What factors are risks? We don't know how they should best cared for in the Neonatal period and how and when and if to follow up. There are factors related to baby, mum, pregnancy, lifestyle, diet etc. How can we identify babies most at risk to put interventions in place. And we want to know what's important to families in Leicester.

Information about 1 of these studies was shared in the previous meeting.

Want to share information on 2 more today.

The idea is to make this information accessible to researchers of the future.

First study is the Leicester Early Birth study. Data collection for 34-38+6 weeks.

Planning to use opt out consent. Ideally when doing research we would like to spend time talking to participants about the study and explaining and asking them to sign to agree to the study. We are not doing for this, all mothers admitted will receive a leaflet that explains baby will be included if born pre 38 weeks and may be included if 39 weeks plus, unless they opt out. They may be contacted for future research unless they opt out. We will them that all data is anonymised but will keep contact details in case need to contact at later date.

This is a slightly different approach but it is becoming more widely used and accepted. Why? To make sure we have complete data. Looking at big study, we need to make sure data is complete. These older babies won't be in hospital as long so difficult to get consent. Babies that are unwell and staying longer are doing so for a reason, and this would then make biased data. We have circulated the leaflet before. Previous feedback was really useful around the language used, and we have changed this to say that most babies do well, rather than focussing on the fact that some babies do not.

Questions for you to consider:

Do you think study is important?

Is opt out consent justified?

Any questions or comments?

MR: [How did you come about with the 2 week opt out?](#)

We felt that would be a reasonable time to allow parents to think and talk about it. Many studies want consent within 24 hours. The plan is that if any data is collected in hospital, it won't be transferred to the University dataset until the 2 week mark.

NT: [When you say you will be giving information out ,is it just the leaflet or will someone come to speak to parents?](#)

EB: Because there are so many people, talking to them individually won't be possible. But the leaflet says clearly if you have questions you can get in touch.

NT: [Do parents always read the leaflets they are given at the time?](#)

Members to consider questions and send over any further thoughts to the NVP lead.

EB: This is a really pertinent point. Another reason why we are giving 2 weeks. Often if given lots of info want to take it home and read it.

HL: Will a poster be put up on the unit too? Parents may not still have the leaflet, and staff won't be talking to them about it? Has any of this gone through a Neonatal psychologist?

EB: The research proposal will go through a much more stringent process than the normal ethics process.

We will definitely have posters in antenatal clinics and in postnatal areas, and on units. And we will be using Social Media to let people know about the study and will also be looking at other media-radio, The Leicester Mercury, and other channels used by our ethnic minority communities.

Want to be aware before they come in of the research.

NT: For those who it is suspected their baby will be born early, will conversations be had with them?

EB: Yes we will have leaflets to share. We will try to make the study as high profile as we can. The hope is that people will know about it beforehand, through publicity around it.

Next Study:

Leicester Late Preterm and Early Term Growth Study

For this study we will be collecting signed, informed consent., rather than using the opt out model.

It's an observational study, so not giving any medicine or procedures. We will be looking at body composition and growth outcomes, and how this is associated with milk feeding in early life.

Currently there is very mixed information about how these babies do in terms of growth in the first 3 months. Some studies say they don't grow well, end up being smaller and shorter, and others say they are at risk of obesity, diabetes and cardiovascular disease. So we think this research is potentially important. We will carry out measurements with special equipment (see slides). The final set of measurements would be carried out by the researcher in peoples homes.

Questions:

Is the study important?

Is the number of measurements acceptable?

Is it acceptable to do home visits?

Any other comments or questions?

NW: Would she look at weight at any other point? Later maybe when they hit school age, as weight varies so much?

EB: Not in this study as she only has 4 years to do her PHD. But this is why we hope to have data from this period, so someone else can look at it later, possibly someone from paediatrics, with further funding. But really important to follow this through.

NT: Will these leaflets be available in other languages?

EB: This is a really difficult one. Previously, have been told that if a member of the community is unable to converse fluently in enough English, they are often unable to read their own lang or speak a particular, difficult dialect.

NT: Can appreciate that, but particularly with previous study, am concerned people will be enrolled in a study they know nothing about.

EB: I completely accept that and agree, but don't know how to get around that. Very difficult with availability of translators, etc. Some languages are difficult to translate into to make sure the message has been accurately translated. If you have any advice, would be really pleased to take that on board.

HL: I could look at top languages in the region and perhaps reach out to trust interpreters. Also, if you are only able to take on people fluent in English will that affect results?

EB: For this study we will make sure there are translators, because the clinical team are communicating with them in some way. Definitely open to using interpreters in this study. The other is more difficult.

BB: Just want to clarify-there is a lot of concern around opt out consent, but it is something used in lots of other areas, eg Social Media. It's a way of being able to gather more numbers and get better data. It doesn't gather a lot of data that people don't share in other ways. Not justifying it, but trying to help lessen the worry. Also, it goes through an ethics committee that have all these concerns. They will check it doesn't have an impact on future care. But absolutely agree they have to have opt out.

NT: That's a good point.

EB: The ethics committee want to know that we have discussed with members of public and parents/patients to make sure no stone is left unturned to make it as acceptable as possible. Whatever you tell me tonight or if you share feedback later on will be really important. And we can say it's been discussed.

NT: If any questions or comments get in touch and we can feedback to Elaine.

EB: Honestly, any feedback is great. Research is nothing if not acceptable to the people it's intending to benefit.

Members to share any further thoughts/ feedback with NT and it will be passed on to EB.

<p>6.</p>	<p>Any Other Business; HL: Wanted to take the opportunity to explain more about a Neonatal network. My role is in Family Integrated care and my job is to keep everything in line and make sure everyone is following same themes. We would like to see whole of the East Midlands doing the same things, so if you experience a transfer, everything is the same. The Competencies wording comes from us, and we hate term too, and are looking to update this. If anyone wants to get involved with this get email from NT. An Amazon Wish-list is great. Used this on my old unit used and it worked well. PAG is similar to this but regional, where we share co-production that is happening across the region. Leicester don't have a parents' Facebook group. A lot of other units do offer this. This is a really helpful resource, so perhaps something to look at in the future. Ladies at Adapt were keen to look at this.</p> <p>We will be creating some 3D Neonatal tours. A bit like Google Street View. Coming soon for Leicester for neonates. So if moving units can have a virtual look around. Hopefully get rid of anxieties.</p> <p>NT: Thanks to Elaine and Tilly for the updates, and thanks to everyone for joining.</p>	<p>Members who want to get involved with redeveloping 'competencies' booklet to get in contact with NT</p>
<p>7.</p>	<p>Date of next meeting; TBC</p>	