

## YORKSHIRE & HUMBER NEONATAL ODN CLINICAL FORUM (NORTH)

**TUESDAY 1 OCTOBER 2019, 9.00 AM - 12.30 PM**

NORMANTON GOLF CLUB, HATFEILD HALL, WAKEFIELD, WF3 4JP

*This meeting has been supported by Cheisi through the purchase of exhibition space*

| Present   | Apologies   |
|---|---|
| <ul style="list-style-type: none"> <li>• Sharon Addey, Lead Nurse, York Teaching</li> <li>• Matthew Babirecki, Consultant Paediatrician, Airedale</li> <li>• Sobia Bilal, Clinical Lead, Harrogate &amp; District</li> <li>• Tracey Cole, Network Co-ordinator, ODN</li> <li>• Siobhan Conlin, Matron, Leeds Teaching</li> <li>• Jennifer Copeland, Chiesi</li> <li>• Louise Crabtree, Lead Nurse ODN (Joint Chair)</li> <li>• Eilean Crosbie, Consultant Paediatrician, Calderdale &amp; Huddersfield (Joint Chair)</li> <li>• Laura Ealham, Lead Nurse NNU, Leeds Teaching</li> <li>• Denise Evans, Lead Nurse, ODN</li> <li>• Catriona Firth, Bradford Teaching</li> <li>• Kelly Gill, Team Leader SNB, Leeds Teaching</li> <li>• Lisa Gorry, Project Support Lead, ODN</li> <li>• Catherine Harrison, Neonatal Clinical Lead, Embrace</li> <li>• Carol Hudson, ANNP, Bradford Teaching</li> <li>• Ashley Jennings, Information Officer, ODN</li> <li>• Kate Lamming, NICU Manager, Hull</li> <li>• Aparna Manou, Consultant Neonatologist, Hull</li> <li>• Lesley Matthews, Neonatal Outreach Sister, Mid Yorks</li> <li>• Lawrence Miall, Consultant Neonatologist, Leeds</li> <li>• Carolyn Pickles, Senior Sister, NNU, Leeds Teaching</li> <li>• Jo Preece, Consultant Neonatologist, Hull</li> <li>• Kirsty Randell, Matron for Children's Services, Airedale</li> <li>• Sunita Seal, Consultant Neonatologist, Bradford</li> <li>• Eamonn Sheridan, Consultant Geneticist, Leeds Teaching</li> <li>• Hannah Shore, Consultant Neonatologist, Leeds</li> <li>• Kallinath Shyamanur, Clinical lead, Mid Yorks</li> <li>• Louise Smith, Senior Sister, Mid Yorks</li> <li>• Vicky Smith, Senior Sister, SCBU, York</li> <li>• Sarah Szpara, Ward Manager, Airedale</li> <li>• Hazel Talbot, Consultant/Education &amp; Guideline Lead, Embrace</li> <li>• Sam Wallis, Consultant Paediatrician, Bradford</li> <li>• Kelly Young, Matron, Bradford</li> </ul> | <ul style="list-style-type: none"> <li>• Bethany Andrew, Network Educator, ODN</li> <li>• Louise Armitage, Bradford Teaching</li> <li>• Jo Bexon, Information Officer, ODN</li> <li>• Gwynn Bissell, Lead Educator, Leeds GI</li> <li>• Charlotte Bradford, Senior Information Manager, ODN</li> <li>• Chris Day, Consultant Neonatologist, Bradford Teaching/Clinical Lead Y&amp;H Neonatal ODN</li> <li>• David Gibson, Consultant Neonatologist, Pinderfields</li> <li>• Luke McLaughlin, Deputy Clinical Lead, York</li> <li>• Sandeep Sandhu, Consultant Paediatrician &amp; Neonatal Lead, York</li> <li>• Marie-Ann Kelly, Network Educator, ODN</li> <li>• Sue Peak, Lead Nurse, Leeds Teaching</li> <li>• Sam Plets, Lead Midwife TCCC, Leeds Teaching</li> <li>• Kay Rushforth, Head of Nursing for Paediatrics &amp; Neonates, Bradford Teaching</li> <li>• Karin Schwarz, Calderdale and Huddersfield</li> <li>• Peter Standring, Consultant Paediatrician, Scarborough</li> <li>• Heather Stuart, Ward Manager, Harrogate</li> <li>• Jo Whiston, Lead Nurse, Embrace</li> <li>• Edith Wilson, Bradford Teaching</li> </ul> |

| No. | Item  | Action     |
|-----|---|------------|
| 1.  | <p><b>Welcome &amp; Introductions</b></p> <ul style="list-style-type: none"> <li>• LCr welcomed all to the meeting and apologies were noted.</li> </ul>   |            |
| 2.  | <p><b>Minutes of previous meetings:</b></p> <ul style="list-style-type: none"> <li>• <b>Clinical Forum North meeting held 25 June 2019</b><br/>The minutes of the previous meeting were agreed as an accurate record.</li> </ul>  |            |
| 3.  | <p><b>Matters Arising</b></p> <ul style="list-style-type: none"> <li>• The new structure of the agenda for Clinical Forum North meetings was noted.</li> <li>• HT described that a 'how to' guide on exome sequencing was presented to Forum members recently. HT had received feedback from Sheffield Children's Trust that they would prefer to work on an individual basis and it was therefore agreed that the 'how to' guide will be a North only guideline. HT confirmed the 'how to' guide is now available on the website.</li> </ul>   |            |
| 4.  | <p><b>Clinical Topics</b></p> <ul style="list-style-type: none"> <li>• <b>NICE Guideline 124: Specialist neonatal respiratory care for babies born preterm</b> <a href="https://www.nice.org.uk/guidance/ng124">https://www.nice.org.uk/guidance/ng124</a></li> </ul> <p>LM gave a presentation on the NICE guideline which was approved in April 2019. All were encouraged to consider the guidance as a team; assess their service against the guideline using the baseline assessment tool; change what can be changed; plan and discuss whatever cannot; and decide how to move forward in order to achieve compliance.</p> <ul style="list-style-type: none"> <li>• <b>Case presentation - Exome sequencing "if you can't label the phenotype can going straight to genome help"</b></li> </ul> <p>CF gave a presentation on exome sequencing. CF described a recent case in which a baby was eventually diagnosed with Perlman Syndrome. It was noted that 53% of babies diagnosed die within the neonatal period. The parents were very keen for their baby to receive a diagnosis, and this was also noted to be important for their future family planning. There was good engagement between the genetic and neonatal teams. CF commented that one of the most important lessons she learnt from this case was how essential it to note any dysmorphic features that are present.</p> | <b>All</b> |
|     | <ul style="list-style-type: none"> <li>• ES gave a presentation on the investigation of the case described by CF. An antenatal array CGH (comparative genomic hybridisation) was undertaken on the baby in order to detect any possible chromosome change and the results came back normal. Due to the baby's unusual abdominal appearance and very large kidneys, a further sample was sent to Exeter for whole exome sequencing. ES and his colleague looked at the results again and decided to look at all genes that cause big baby syndrome, looking for a point mutation however none were found. They then moved on to CNV sequencing and this confirmed a diagnosis of Perlman Syndrome. This case has demonstrated the benefits and draw backs to the new approach. ES emphasised that obtaining a diagnosis is contingent on colleagues working together.</li> </ul>   |            |

| No.              | Item  | Action   |
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|                  | <p>ES informed the group that there were previously differences between antenatal and postnatal Array CGH testing. SS asked if this was still the case. ES will make enquiries and report back to the group.</p>  | <p><b>ES</b></p>                                     |
|                  | <p>A promotional product presentation was delivered by Jennifer Copeland of Chiesi, who were sponsoring the Forum meeting.</p>  |  |
| <p><b>5.</b></p> | <p><b>Network Topics</b></p> <ul style="list-style-type: none"> <li>• Clinical Lead Update: <ul style="list-style-type: none"> <li>○ <b>Neonatal Critical Care Transformation Project (previously Better Newborn Care)/Transformation/Extreme Preterm BAPM document update</b><br/> The group were informed that there was a further delay with the publication of the document with a new release date potentially in December 2019. It was noted that when the document comes out there may be a less rigid approach around the accepted amount of activity care days when looking at resignation of units.</li> <li>The consultation period for the Perinatal management of extreme preterm birth before 27 weeks of gestation: A Framework for Practice BAPM document was now over. While awaiting the outcome of the consultation, all were asked to start thinking about in utero transfers 22-23 weeks gestation, this would be significant for maternity and neonates, as well as the active care options that are going to be offered.</li> <li>○ <b>Clinical Reference Group</b><br/> It was noted that an updated neonatal service specification document will hopefully be available in 2020.</li> <li>○ <b>Recording Encephalopathy on BadgerNet</b><br/> The group was informed that there had been an issue on one of the units with regard to data recording of HIE, and its associated signs and symptoms on BadgerNet. The unit had been identified by the NMPA (National Maternity Perinatal Audit) as recording particularly high numbers of HIE.</li> <li>NMPA gather data on all 35+ singletons with 3 signs and symptoms 1. Consciousness, 2. Tone, 3. Convulsions, the Network has since assisted the unit with the cleansing of their data. Some of the signs and symptoms were attributable to other conditions and not just HIE. It was also noted there was lots of variation in the grading of HIE for those particular babies transferring to other units for treatment. All were encouraged to be aware of the above when inputting data. Please ensure that all data particularly around HIE grading, that the final diagnosed grade was correct at time of discharge. The Network has informed NMPA of potential issues around the information they are collecting. NNAP will no longer be recording the above data as the content was poor.</li> <li>Jo Bexon will be circulating guidance to assist with appropriate recording shortly.</li> </ul> </li> </ul> | <p><b>All</b></p> <p><b>All</b></p> <p><b>JB</b></p> |

| No. | Item  | Action                 |
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|     | <ul style="list-style-type: none"> <li>○ <b>Service Reviews</b><br/>LCr informed the group that most Service Reviews dates have now been confirmed. A proforma with topics will be included in the Service Review packs.</li> <li>○ <b>NNAP data so far – 2 year follow up</b><br/>HT informed the group that a request had been made to raise this item at the Forums in order that colleagues can share ideas of how we can do this better. LM commented that there is a tool on BadgerNet that tells you when the baby's follow up is due.<br/><br/>It was agreed that a Champion of Good practice will be sought to talk at the next Forum.</li> </ul>  | HT/Admin               |
|     | <ul style="list-style-type: none"> <li>● <b>Lead Nurse Update:</b> <ul style="list-style-type: none"> <li>○ <b>Thermoregulation/ATAIN/TC</b><br/>DE asked all to ensure they are aware of their ATAIN lead. LM suggested that at the next meeting Trusts share experiences. It was suggested that midwives be invited to the next meeting to discuss improvements introduced in their Trust that had made a difference.<br/><br/>Thermoregulation information sent out from AJ, ODN Information Team, was considered very helpful by all. A request was made that a run chart for each unit be included in order to show progress. AJ to action.</li> <li>○ <b>Staffing/workforce</b><br/>DE gave an update on staffing and workforce within the Network. It was agreed that DE would action the request for information with regard to workforce baseline figures.</li> <li>○ <b>Parent Passport Family Integrated Care Update</b><br/>LCr informed colleagues that following a recent parent passport meeting the group will now start introducing the FiCare model/ family Involvement in care to their individual units. The first part of the process will be an introduction to the model using a poster presentation primarily aimed at the staff. A resource file for staff to access will also be made available. It was felt as a group that the whole care package that parents work through should be the same for all the Network units, and as such the group would consider/utilise packages that were already available to avoid re-inventing the wheel.</li> </ul> </li> </ul> | DE<br><br>AJ<br><br>DE |
| 6.  | <p><b>Education &amp; Guidelines:</b></p> <ul style="list-style-type: none"> <li>● <b>Education Days</b><br/>HT provided an update and informed the group of the following events: <ul style="list-style-type: none"> <li>○ A communication event is scheduled for the 10 October 2019 in Sheffield.</li> <li>○ A cardiac event will take place on 23 January 2020, in Leeds.</li> <li>○ The Neonatal Conference has been confirmed for the 5 May 2020, the venue is likely to be Wetherby.</li> <li>○ An event will take place on 21 May 2020, in Pinderfields if possible. If a room is not available at Pinderfields HT will request a venue at Barnsley.</li> </ul> </li> </ul>   | HT                     |

| No. | Item   | Action                          |
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|     | <ul style="list-style-type: none"> <li>• <b>Guidelines Update</b><br/>HT informed the group that it was agreed at Execs that a group of volunteers would be sought to help look at the LISA guideline. HT asked that anyone from a Level 2 unit who would like to be involved please contact her. EC will ask her colleagues. It is hoped that following circulation to Clinical Leads, both Medics and Nursing that this guideline can be presented at the December Exec Group for ratification.</li> <li>• <b>Lunchtime teaching "webinars"</b><br/>HT informed colleagues of teaching webinars that the team would like to provide once a month. Perhaps a 40 min session on specific topics such as QIS. It was agreed that a recorded version may be more practical, such as a 20 minute podcast. As the Network's website can be constraining HT will look at other platforms through which this can be delivered, such as Vimeo.</li> </ul> <p>With regard to the attendance of neonatal grid trainees, it was agreed that each tertiary unit would email a list of their current trainees to ODN admin so that they could be included in the circulation of future meetings. A request was also made for all units to email ODN Admin once trainees leave.</p> | <p>HT</p> <p>Tertiary Units</p> |
|     | <ul style="list-style-type: none"> <li>• <b>Nurse Educators:</b> <ul style="list-style-type: none"> <li>○ Update on Education &amp; QIS           <ul style="list-style-type: none"> <li>▫ DE met with The Education Programme Manager, West Yorkshire &amp; Humber. It was noted that going forward all funding will go to units based on a head count of each Trust.</li> <li>▫ With regard to QIS, there was an opportunity with Hull &amp; York University to move funds across boundaries but not counties. Please can people contact DE with any queries.</li> <li>▫ A mapping meeting will take place on Thursday regarding the foundation part of the course.</li> </ul> </li> </ul> </li> </ul>   | <p>All</p>                      |
| 7.  | <p><b>Information &amp; Data</b></p> <ul style="list-style-type: none"> <li>• <b>Dashboards – Local &amp; National</b><br/>LCr asked if all were content with the new presentation of the dashboards and this was agreed.</li> <li>• <b>Exception Reporting (Round Table Discussions)</b><br/>HT facilitated the group discussions for 11 exceptions which had taken place across the North of the Network from June 2019 to August 2019. All cases were closed, with the exception of the following:           <ul style="list-style-type: none"> <li>▫ Case 9 (A73NUC) – further information/review required.</li> <li>▫ Case 10 (A8CMUC) – further information/review required.</li> </ul> </li> </ul> <p><b>Learning Points identified:</b> It is important to seek advice from Embrace/Tertiary Centres and to ensure that discussions are recorded appropriately.</p> <p>A query was raised asking whether discussions with Tertiary Centres/Embrace could be recorded on BadgerNet. LMG to enquire and report back.</p>   | <p>All</p> <p>LMG</p>           |

| No. | Item  | Action                                      |
|-----|---|---|
|     | <p><b>Post Meeting Note:</b> All Units are notified on a monthly basis of any off pathway care/deliveries which have taken place at their unit the month prior. Additional information is requested from Units in order that these cases may be reviewed/discussed by the group at forthcoming Clinical Forums and that Learning Points may be identified if relevant (all &lt;27 Week delivery notifications are forwarded by the Information Team to Midwifery colleagues to investigate).</p>  |   |
|     | <ul style="list-style-type: none"> <li>• <b>Y&amp;H Neonatal and Temperature Dashboard</b><br/>The dashboards were presented and the revised layout noted.</li> </ul>   |   |
| 8.  | <p><b>Any Other Business</b></p> <ul style="list-style-type: none"> <li>• <b>Car seats</b><br/>LCr asked all to be aware of the RoSPA Road Safety Research guidance.</li> <li>• <b>Transwarmers</b><br/>A MRHA alert had been circulated about transwarmers. HT reminded the group that when you activate the transwarmer, it warms up by 10 degrees. Be aware not to activate it inside the incubator or whilst on the Resusitaire while on as this could burn the baby. Do not store it in incubator, rather store it at normal room temperature and activate it outside of the incubator. Good temperature monitoring of your baby is essential to ensure safety. MRHA compliance forms are to be completed.</li> <li>• <b>Embrace – alternative ways of babies travelling with mothers</b><br/>LCr informed the group of a trial to transport mothers and babies together using a harness for well babies and mothers.</li> <li>• <b>BAPM toolkit</b><br/>All were asked to be aware of ideas included in this document of how to reduce hypothermia.</li> <li>• <b>NICE guideline on Neonatal Post Mortems</b><br/>This document is currently out for consultation.</li> <li>• All were asked to ensure good communication with maternity colleagues when looking to accept in utero transfers so that they are aware of any outstanding repatriation for their units, as these should take priority.</li> </ul> | <p>All</p> <p>All</p> <p>All</p> <p>All</p> |
| 9.  | <p><b>Dates and times of future meetings</b></p> <p><b>Clinical Forum</b></p> <ul style="list-style-type: none"> <li>• 2020 dates to be confirmed. <ul style="list-style-type: none"> <li>• Joint Forum with Maternity Network - 13 November 2019</li> </ul> </li> </ul> <p><b>Mortality Review Panel - North</b> (<i>all meetings follow on from Clinical Forums</i>)</p> <p><b>Executive Group Meetings</b></p> <ul style="list-style-type: none"> <li>• Thursday 5 December 2019, 1.30 – 4 pm, Hatfeild Hall</li> <li>• Thursday 5 March 2020, 1.30 – 4.00pm, Hatfeild Hall</li> <li>• Thursday 11 June 2020, 1.30 – 4.00pm, Hatfeild Hall</li> <li>• Thursday 3 September 2020, 1.30 – 4.00pm, Hatfeild Hall</li> <li>• Thursday 3 December 2020, 1.30 – 4.00pm, Hatfeild Hall</li> </ul>   | Admin                                       |