

## YORKSHIRE & HUMBER LONG TERM VENTILATION WORKING GROUP

<b>Date and time</b>	Monday 17 June 2019, 10:00am – 12:00pm
<b>Venue</b>	Annabel Room, Hatfield Hall, Normanton Hall Golf Club, Aberford Road, Wakefield, WF3 4JP
<b>Chair</b>	Sian Cooper, Clinical Lead (North), Yorkshire & Humber Paediatric Critical Care ODN

Attendance	
Name	Role & Organisation
Caroline Savage	Senior Staff Nurse, Paediatric DHU, Hull
Emma Green	Service Specialist, North England Specialist Commissioning Team
Heidi Reynolds	Paediatric Respiratory Physiotherapist, Bradford
Jessica Oldfield	Consultant and E-MAP lead, Embrace Transport Service
Jo Lumsden	Consultant Paediatric Intensivist, Leeds Children's Hospital
Karen Perring	Lead Nurse, Y&H Paediatric Critical Care ODN
Kelechi Ugonna	Consultant Respiratory Paediatrician, Sheffield Children's Hospital
Lee Richardson	Clinical Nurse Ventilation Specialist, Sheffield Children's Hospital
Lisa Cutsey	Lead Nurse, NEY&H Paediatric Neuroscience Network
Martin Quinton	Critical Care Practitioner, Sheffield Children's Hospital
Matthew Kurian	Consultant Paediatrician, Doncaster & Bassetlaw
Murray Wheeler	Consultant Paediatrician, York
Paula Graham	Children's Nurse, Barnsley Hospital
Rum Thomas	Consultant Paediatric Intensivist, Sheffield Children's Hospital
Sarah Georgiades	Team Leader Children's Nurse Specialist, Leeds Children's Hospital
Sharon Sloan	Children's Nurse Specialist, Leeds Children's Hospital
Sian Cooper	Clinical Lead (North), Yorkshire & Humber Paediatric Critical Care ODN
Vanessa Craven	Specialist Trainee in Respiratory Paediatrics, Sheffield Children's Hospital
Carolyn Maundrill	Continuing Care Co-ordinator for Critical Care, Sheffield Children's Hospital

Apologies	
Name	Role & Organisation
Andrea Bliss	Matron, Doncaster & Bassetlaw
Anne Donkin	Information Support Officer, ODN
Anil Shenoy	Consultant Paediatrician, Bradford
Ann-Marie Childs	Consultant Paediatric Neurologist, Leeds Children's Hospital
Christopher Edwards	Consultant Respiratory Paediatrician, Leeds Children's Hospital
Eduardo Moya	Consultant Paediatrician, Bradford
Emma Andrews	Network Manager, Yorkshire & Humber Paediatric Critical Care ODN
Haji Sheeraz Khan	Consultant Respiratory Paediatrician, Hull & East Yorkshire Hospital
Hemant Kulkarni	Consultant Respiratory Paediatrician, Sheffield Children's Hospital
Karen Pysden	Consultant Paediatric Neurologist, Leeds Children's Hospital
Kathryn Davison	Consultant Paediatrician, Mid Yorkshire Hospitals
Sarah Cockcroft	Practice Educator, Martin House Hospice
Sarah-Jane Foxton	Consultant Paediatrician, Harrogate District Hospital

		Action
1.	<b>Welcome, apologies and introductions</b>	
2.	<b>Minutes of the last meeting 26 March 2019 - agreed</b>	
3.	<p><b>Agreed actions 26 March 2019</b></p> <ul style="list-style-type: none"> <li>• Minutes from initial parent and carer focus groups in Sheffield &amp; Leeds circulated to LTV Working Group</li> <li>• Ambulance service process for adding “flag” on system for all patients confirmed and emailed to CM and SG.</li> <li>• Educational session offered to ED in Leeds</li> <li>• Letter of support for LTV business case &amp; LTV minutes sent to Leeds</li> <li>• Honorary contract process from Calderdale to support LTV carers working in hospital - emailed to KP - feedback that process looks quite complicated <ul style="list-style-type: none"> <li>○ Update was provided from Leeds, the adult service pay carer policy has recently been used for a child with delayed planned discharge. Hoping to use for other patients in the future. Sarah Georgiades will email the Leeds Carer Policy to SC and KP, this can then be available for other hospitals if they wish to adopt / modify.</li> <li>○ MW to investigate whether an equivalent of the Leeds Carer Policy exists in York that could be applied to other DGHs</li> <li>○ Midlands Children’s LTV network conference flyer circulated - HR will report back to the Working Group.</li> </ul> </li> </ul> <p>All other actions are on the agenda as separate items.</p>	<p>SG</p> <p>MW</p>
4.	<p><b>Parent and carer support groups and engagement - progress report</b></p> <p>Peer support and BLS training to be offered quarterly in Sheffield. CM to report back next time.</p> <p>SG commented that although a Facebook page had been considered, parents were generally not in favour of this.</p> <p>SC to speak with Mark Powers in Leeds to discuss a joint session for BLS, including tracheostomy families. SG offered to help with this.</p> <p>MK informed the group of a useful training session organised by Royal Brompton in London where carers and families attend. A follow up day was also arranged. SC asked if these sessions were available widely. MK said they were only available for London residents. MK to send the Royal Brompton Hospital simulation training programme for carers and families to SC.</p> <p><b>Discussion followed about educational sessions for professionals</b></p> <p>Discussed development of educational sessions and tools, and who would be able to lead on this kind of work. SC to speak to Chris Edwards regarding the potential for a Y&amp;H Future Leaders Fellowship bid, to include the development of online educational tools for medical and technical advice targeting both carers and professionals for LTV patients.</p>	<p>SC</p> <p>MK</p> <p>SC/CE</p>

	<p>MK suggested an “open day” and a Y&amp;H respiratory network educational day is currently being planned, theme yet to be confirmed. KU to liaise with CE to discuss the format and report back to the group in 3 months.</p> <p>With regard to the monthly workshops held in Leeds it was agreed these could be opened up to all professionals in the region. MW suggested it would be useful to have local champions in attendance and nurse educators who could disseminate the information back to their teams. SS will forward future flyers to SC for dissemination to the LTV Working Group and the Paediatric Critical Care ODN membership.</p> <p>It was agreed the Y&amp;H Paediatric Critical Care ODN Clinical Forum in March 2020 will be around the theme of LTV / technology dependent children.</p>	<p><b>KU</b></p> <p><b>SS</b></p> <p><b>SC/RT</b></p>
5.	<p><b>Mapping exercise for Y&amp;H LTV patients (including NIV)</b></p> <p>LR to send SC the breakdown of regional data on total numbers of South Yorkshire LTV patients, including a breakdown of DGH patients.</p>	<p><b>LR</b></p>
6.	<p><b>5 year data from Critical Care Units</b></p> <p>JL gave the Leeds PICU data for LTV patient numbers (19) over the past 5 years, including those in level 3 beds medically fit for discharge. It was highlighted that critical care is not always the most appropriate place in terms of patient experience or critical care capacity.</p> <p>MW commented on the unmet need in West Yorkshire. SC confirmed the ODN have written in support of this issue as an action of the last meeting.</p> <p>KP suggested it would be helpful when prioritising future training and support if we understand the needs of each DGH. It was agreed that KP and Anne Donkin (ODN information support) will bring together the whole region data on LTV patients to inform future planning of education and training.</p>	<p><b>KP</b></p>
7.	<p><b>Pathways for LTV patients who are acutely unwell or injured</b></p> <p>Vanessa Craven, Senior Trainee in Respiratory Paediatrics has volunteered to lead this work. Contact had been made with representatives from DGHs, Tertiary Units and Embrace.</p> <p>VC has looked at some of the other LTV team practices around the country including Newcastle, Manchester and Stoke, all of whom have different set ups for their service and all of whom have LTV units in their tertiary hospitals. We discussed the current set up in Sheffield and Leeds.</p> <p>Objectives from today’s discussion for the acute pathway group:</p> <ul style="list-style-type: none"> <li>• Work towards areas of consensus on thresholds for admission and transfer in acute respiratory illness, other acute illness, and injury</li> <li>• Mechanisms for providing advice - who / when / how</li> <li>• Consideration of existing resources in the North and the South</li> <li>• JL will try to organise PPM+ access (Leeds electronic record) for Embrace to be able to access</li> </ul>	<p><b>VC</b></p> <p><b>JL</b></p>

8.	<p><b>Framework for decision making process in Leeds</b></p> <p>CE not present to update.</p>	
9.	<p><b>Online FAQ for parents and carers</b></p> <p>In the absence of 24/7 advice a FAQ microsite for Leeds would be possible. Lee Richardson commented that he is working on a FAQ list at the moment.</p> <ul style="list-style-type: none"> <li>• LR to send FAQ list to SG and SS.</li> <li>• JO to send separate Embrace FAQ list to LR.</li> <li>• SG to send the Unlocking Procedures to JO.</li> </ul>	<p><b>LR</b> <b>JO</b> <b>SG</b></p>
10.	<p><b>Commissioning update</b></p> <p>The key issues and impact of commissioning barriers was discussed. A Regional CCG Forum (N&amp;S) meeting took place last week and it was agreed that EG would send a written summary of issues/progress to SC.</p> <p>JL will send Leeds costing data to EG.</p>	<p><b>EG</b> <b>JL</b></p>
11.	<p><b>Neonatal representative</b></p> <p>Requested via the Neonatal ODN, still no neonatal representation. JO will represent the South for neonates and will also try to identify a representative for neonates in the North. SC will also contact colleagues in Bradford to seek interest.</p>	<p><b>JO/SC</b></p>
12.	<p><b>Any other business</b></p> <p>HR will send the Community Paediatric Physiotherapy commissioning tool for circulation to the group by SC.</p>	<p><b>HR</b></p>
13.	<p><b>Date and time of next meeting - September 2019</b></p> <p>Doodle poll to be sent for September 2019.</p>	<p><b>Admin</b></p>