

# YORKSHIRE & HUMBER LONG TERM VENTILATION WORKING GROUP

<b>Date &amp; time</b>	Tuesday 9 September 2020, 10 am – 12 noon
<b>Venue</b>	Via Microsoft Teams
<b>Chair</b>	Sian Cooper, Clinical Lead (North), Yorkshire & Humber Paediatric Critical Care ODN

<b>Attendance</b>	
<b>Name</b>	<b>Role &amp; Organisation</b>
Kelechi Ugonna	Consultant in Paediatric Respiratory Medicine, SCH
Andrea Bliss	Associate Director of Nursing, Children's and Neonates, DBTH
Amika Challacombe	Home Ventilation Nurse, Sheffield Children's Hospital
Sian Cooper	Clinical Lead (North) Y&H Paediatric Critical Care ODN
Christopher Edwards	Consultant Respiratory Paediatrician, Leeds Children's Hospital
Anil Shenoy	Consultant Paediatrician, Bradford
Kay Rushforth	Head of Children's Nursing, Bradford
Anne Donkin	Project Lead, Y&H PCC and SIC ODN
Karen Perring	Network Manager and Lead Nurse, Y&H Paediatric Critical Care ODN
Sarah Georgiades	Team Leader Children's Nurse Specialist, Leeds Children's Hospital
Lisa Cutsey	Ronald Dahl Transition Neuromuscular Transition Nurse, Leeds
Alison Outhwaite	Children's Community Nurse, Barnsley
Vanessa Craven	Consultant Paediatrician, SCH
Tallal Hussain	Consultant Paediatrician, Bradford
Clair Scaife	Matron, Rotherham
Mathew Kurian	Consultant Paediatrician, DBTH
Sarah-Jane Foxton	Consultant Paediatrician, Harrogate
Vanessa Brown	Senior Matron, Hull
Helen Moore	Consultant Paediatrician, Chesterfield
Murray Wheeler	Consultant Paediatrician, York

<b>Apologies</b>	
<b>Name</b>	<b>Role &amp; Organisation</b>
Emma Andrews	Network Manager, Yorkshire & Humber Paediatric Critical Care ODN
Emma Green	Service Specialist, North England Specialist Commissioning Team
Heidi Reynolds	Paediatric Respiratory Physiotherapist, Bradford
Karen Pysden	Consultant Paediatric Neurologist, Leeds Children's Hospital
Vikki McAlpine	Paediatric Manager, NLAG
Shane Atkins	Community Children's Care Assistant, Rotherham
Elizabeth Herreiven	Consultant in Emergency Medicine and Paediatric Emergency Medicine
Carolyn Maundrill	Continuing Care Co-ordinator for Critical Care, Sheffield Children's Hospital
Sharon Sloan	Children's Nurse Specialist, Leeds Children's Hospital
Eduardo Moya	Consultant Paediatrician, Bradford
Sarah Cockcroft	Admissions Liaison Nurse / Care Team Nurse, Martin House
Anne-Marie Childs	Consultant Paediatric Neurologist, Leeds
Claire Windsor	Consultant, Leeds
Sarah Hibbert	Leeds

		Action
1.	<p><b>Welcome, apologies and introductions</b></p> <p>SC welcomed all to the meeting. Introductions were made and apologies recorded above.</p>	
2.	<p><b>Minutes of the last meetings held 4<sup>th</sup> February 2020</b></p> <p>The minutes of the last meeting were agreed as an accurate record.</p>	
3.	<p><b>Agreed actions 4<sup>th</sup> February 2020</b></p> <ul style="list-style-type: none"> <li>Acute Pathway Sub Group has now met and produced the first draft. This was discussed as part of agenda item 4.</li> <li>Feedback letter was written to parents and carers and sent out to LTV centres to send out</li> <li>Terms of Reference has been agreed and written up.</li> <li>Agreed that anaesthetic and ED representation was needed at the Acute Pathway Sub Group. This has been achieved with 2 anaesthetists and 1 ED consultant.</li> <li>Sent out 1 policy from Bradford about Nasopharyngeal suction in the community and this has been sent out to the group.</li> </ul> <p>All other actions are listed as separate agenda items.</p>	
4.	<p><b>Acute pathway Sub Group for LTV patients who are unwell or injured - progress report</b></p> <ul style="list-style-type: none"> <li>Vanessa Craven updated the group regarding the first draft of the pathway. Designed to make some broad clear statements. Can be found on the Y&amp;H PCC ODN website. The group agreed that the document lays out where we are with regard to trying to transfer some of these patients. The group was asked to feedback to Vanessa but overall everyone was happy with the document. Once agreed with the Sub Group and the LTV Working group it can be shared more widely.</li> </ul>	VC
5.	<p><b>Minimum standards of care for private care agencies.</b></p> <p>Previously discussed developing a Minimum Standard of care for private agencies to support the delivery of consistent and quality services. AC and SG were assigned to this. Unfortunately due to the COVID situation this hasn't been started. Agreed for draft to be ready in time for the next meeting in March.</p>	AC/SG
6.	<p><b>Online FAQ questions for parents and carers</b></p> <p>A list of questions had previously been agreed. The next step was for a group to put together the answers to those questions. AC informed the group that answers had been written and sent to Embrace and waiting for response to see if they meet the needs they have. Videos have been uploaded to the SCH website on ventilation set up and use and also a password protected area for unlocking the ventilators for the DGH's to use in the meantime. CE advised that some progress has been made in Leeds as they now have a website to put things on. SC to chase the list of answers with Lee. Leeds very short</p>	AC/SG  SC

		Action
	staffed so struggling to get this up and running. Agreed to be completed by the next meeting. SCH document to be shared with Leeds.	
7.	<p><b>Embrace FAQ</b></p> <p>Sian to email Jess Oldfield at Embrace to chase up and finalise.</p>	SC
8.	<p><b>Y&amp;H PCC ODN Clinical Forum feedback- LTV</b></p> <p>One day event hosted by the network on 10<sup>th</sup> March. Feedback was shared with the group. KP provided the update. Really well attended and well received with good engagement. Lots of sharing of practice, learning and ideas. Opportunity to visualise things with the equipment being there and be able to use it. Good idea to run a similar thing again. Every session brought something useful. A second session should include something about complex patients and have a parent speaker. The group agreed it would be a good idea to hold a second event and very valuable.</p>	
9.	<p><b>Commissioning Task and Finish Group</b></p> <p>Unfortunately no commissioning representation in the meeting but no further forward in any of the workstreams. SC and KP to discuss moving forward with HB.</p> <p>KP provided an update on national discussions. Lot of discussion about LTV as a result of the NCEPOD report coming out.</p> <p>South Thames Network has a very active work programme around LTV and KP was invited to join a small working group to discuss where LTV sits in terms of PCC ODN's and what pieces of work are needed going forward.</p> <p>There has been discussion whether the LTV service specification needs rewriting. Also discussed pieces of work such as Acute Pathway which VC has been involved in for Y&amp;H and discharge planning- both deemed valuable.</p> <p>Link to a series of webinars on LTV by our colleagues in South Thames Paediatric Network has been sent out the group by AD. Link can be found below:</p> <p><a href="http://stpn.uk/panthames-ltvincyp/">http://stpn.uk/panthames-ltvincyp/</a></p> <p>SC advised the group that there are 4 other items on the task and finish work stream that need commissioning support and unable to move forward without this.</p> <p>AS (Bradford) suggested to the group that it would be a good idea to introduce Champions in each hospital to be able to link up. KP asked AC and SG if the use of Champion would be a good thing. AC informed that this has been tried in SCH and it worked well in terms of initial stepdown. SG tried numerous times but is difficult having the time and capacity to be able to update and train. KP to contact the DGH's to see if there is any interest and will share and link up the people. AC asked if possible for one in the hospitals and one in the</p>	KP

		Action
	community. KU (SCH) and MW (York) advised better in the bigger units.	
10.	<p><b>Parent and Carer support groups</b></p> <p>Parent and Carer feedback letter hasn't sent out to the families from the group. AC and SG to try and prioritise this.</p> <p>KU shared with the group how much of a brilliant job Lee and Amika have done during this challenging job. CE also shared that SG and SS have also done a fantastic job.</p>	
11.	<p><b>NCEPOD</b></p> <p>CE – Lot in the report we are already doing but the report mentioned psychology and have that in Leeds they have benefited from having psychology support for LTV patients. KU recognised there is a gap in the LTV provision at SCH and it would be helpful if there was a standard requirement to have psychology in LTV remit.</p>	
12.	<p><b>Any other business</b></p> <p>None</p>	
15.	<p><b>Date and time of next meeting</b></p> <p>To be agreed (March 2021) via Microsoft teams</p>	AD

SC- Sian Cooper  
 KP Karen Perring  
 AD Anne Donkin  
 AC Amika Challacombe  
 SG Sarah Georgiades  
 VC Vanessa Craven  
 CE Chris Edwards  
 MW Murray Wheeler  
 KU Kelechi Ugonna