

YORKSHIRE & HUMBER LONG TERM VENTILATION WORKING GROUP

Date & time	Tuesday 3 September 2019, 10 am – 12 noon
Venue	Cedar Court Hotel, Wakefield, WF4 3QZ
Chair	Emma Andrews, Network Manager, Yorkshire & Humber Paediatric Critical Care ODN

Attendance	
Name	Role & Organisation
Alex Paes	Paediatric Registrar, Leeds Teaching Hospitals
Amika Challacombe	Sheffield Children's Hospital
Andrea Bliss	Matron, Doncaster & Bassetlaw
Anne Donkin	Information Support Officer, ODN
Anil Shenoy	Consultant Paediatrician, Bradford
Caroline Savage	PHDU, Hull
Chakraprani Vasudevan	Neonatologist Bradford Teaching Hospitals NHSFT
Emma Andrews	Network Manager, Yorkshire & Humber Paediatric Critical Care ODN
Emma Green	Service Specialist, North England Specialist Commissioning Team
Haji Sheeraz-Khan	Respiratory Consultant, Hull University Teaching Hospitals
Heidi Reynolds	Paediatric Respiratory Physiotherapist, Bradford
Jessica Oldfield	Consultant and E-MAP lead, Embrace Transport Service
Jill Morris	Physiotherapy, Bradford
Jo Lumsden	Consultant Paediatric Intensivist, Leeds Children's Hospital
Karen Perring	Lead Nurse, Y&H Paediatric Critical Care ODN
Kay Rushforth	Head of Nursing, Children's Services, Bradford
Lisa Cutsey	Lead Nurse, NEY&H Paediatric Neuroscience Network
Matthew Kurian	Consultant Paediatrician, Doncaster & Bassetlaw
Murray Wheeler	Consultant Paediatrician, York
Sarah Georgiades	Team Leader Children's Nurse Specialist, Leeds Children's Hospital
Sharon Sloan	Children's Nurse Specialist, Leeds Children's Hospital
Tracey Cole	Network Co-ordinator, Yorkshire & Humber ODN
Vanessa Craven	Specialist Trainee in Respiratory Paediatrics, Sheffield Children's Hospital

Apologies	
Name	Role & Organisation
Carolyn Maundrill	Continuing Care Co-ordinator for Critical Care, Sheffield Children's Hospital
Christopher Edwards	Consultant Respiratory Paediatrician, Leeds Children's Hospital
Eduardo Moya	Consultant Paediatrician, Bradford
Joanne Reed	Clinical Nurse Manager, Paediatrics, Calderdale
Karen Pysden	Consultant Paediatric Neurologist, Leeds Children's Hospital
Kathryn Davison	Consultant Paediatrician, Mid Yorkshire Hospitals
Martin Quinton	Critical Care Practitioner, Sheffield Children's Hospital
Rum Thomas	Consultant Paediatric Intensivist, Sheffield Children's Hospital
Sarah Cockcroft	Practice Educator, Martin House Hospice
Sarah-Jane Foxton	Consultant Paediatrician, Harrogate District Hospital
Sian Cooper	Clinical Lead (North), Yorkshire & Humber Paediatric Critical Care ODN
Stuart Conquer	Principle Physiotherapist in Respiratory Care, Sheffield Children's Hospital

		Action
1.	<p>Welcome, apologies and introductions</p> <p>EA welcomed all to the meeting. Introductions were made and apologies recorded above.</p>	
2.	<p>Minutes of the last meeting held 17 June 2019</p> <p>The minutes of the last meeting were agreed as an accurate record.</p>	
3.	<p>Agreed actions 17 June 2019 (EA)</p> <ul style="list-style-type: none"> • Leeds RTO/LTV planning to offer drop in BLS to trach families It was noted that Leeds are happy to proceed with drop in BLS sessions. A meeting is currently being arranged to agree next steps. • Royal Brompton training families program MK has forwarded this programme to SC as agreed. • Leeds LTV monthly workshop flyers to advertise more widely SS has circulated flyers and confirmed there has been good uptake for the workshops which are specifically for PICU. • Look in to PPM+ access for Embrace JL confirmed that unfortunately it is not currently possible to grant access to Embrace due to IG issues. • Unlocking procedures info to be sent to JO Embrace – SG This action has been completed. • Neonatal representative – confirmed Chakraprani Vasudevan was confirmed as the neonatal representation and was in attendance at today's meeting. • Community paediatric physio commissioning tool circulated This had been circulated. <p>All other actions are listed as separate agenda items.</p>	
4.	<p>Acute pathway Sub Group for LTV patients who are unwell or injured - progress report</p> <p>VC gave an update and explained the aim of the Sub Group which develop an acute care pathway for LTV patients.</p> <ul style="list-style-type: none"> • There has been a marked increase of inpatients between 2011 and 2018 for both NIV and tracheostomy, the cohort has significantly increased. • VC has emailed around DGHs to ask what training is available for medics, nurses and nurse educators. • Training across the patch is variable. Bradford are the only DGH who include tracheostomy training as part of their nurse induction. • It was noted that staff are more confident managing tracheostomy than NIV. • There is low confidence with regard to troubleshooting ventilators. • We need to change how we view the parental role to ensure adequate support 	

		Action
	<p>is provided.</p> <ul style="list-style-type: none"> It was suggested that we may require more Level 2 capacity throughout the Network for this cohort of patients. It was acknowledged that to address this work adequate anaesthesia representation is required. A Working Group is being established to look at developing a local service specification for the provision of level 2 care outside of a tertiary unit. It was confirmed that updates would be reported back to this group. EG confirmed that Commissioners are setting up a Task and Finish Group meeting and asked that should anyone want to be involved, they contact her. There is a need to decide which guidelines, standardisation and training is required for those hospitals who take in these patients. It was suggested that we look at the DGHs who are doing well in this area, ask what is required to ensure continued success and then see how we can replicate this in other DGHs. VC to Undertake further work as per the conversation in this meeting 	<p>All</p> <p>VC</p>
5.	<p>Leeds Carer Policy enabling community carers to work in hospital - progress update (SG)</p> <p>SG confirmed that using an amended version of an existing LTHT form (used in adult services), they have been able to get carer teams in more quickly and this has resulted in faster discharges. It was noted this has not been rolled out to DGHs as yet.</p>	
6.	<p>DGH equivalent to Leeds Carer Policy for adults</p> <p>MW provided an update on the query raised at the last meeting, whether there is a DGH equivalent to the Leeds Carer Policy for Adults? It was confirmed that unfortunately, there nothing similar available for adults.</p>	
7.	<p>Mapping exercise for Y&H LTV patients (including NIV) and planning for education and training needs</p> <p>KP had received information back from LTV teams and agreed with VC to share the information following the meeting. Further mapping work to be undertaken.</p> <p>The Clinical Forum in March 2020 will go ahead and the mapping exercise will provide the items for the agenda.</p>	<p>KP/VC</p>
8.	<p>Y&H respiratory network meeting (KU)</p> <p>KU was not in attendance. EA will email KU for an update which will then be circulated.</p>	<p>EA/KU</p>
9.	<p>Y&H PCC ODN Clinical Forum March 2020</p> <p>As discussed earlier, the focus of this Clinical Forum will be LTV. Should you wish to include anything on the agenda, please contact SC/RT.</p>	<p>All</p>
10.	<p>Y&H Future Leaders fellowship bid (CE)</p> <p>CE was not in attendance. EA will email CE for an update which will then be circulated.</p>	<p>EA/CE</p>
11.	<p>Online FAQ for parents and carers - progress report (LR)</p> <p>KP had circulated the draft FAQ report but had received no comments. KP agreed to recirculate the document and asked that feedback is sent directly to LR.</p>	<p>All/ Admin</p>

		Action
12.	<p>Embrace FAQ list (JO) JO gave an update on the FAQ list. It was agreed that the Embrace website is a good place to store information (password protected). JO will send the FAQ list to both SCH and LTHT PICUs.</p>	JO
13.	<p>Commissioning update:</p> <ul style="list-style-type: none"> • Summary of key issues and impact of commissioning barriers As discussed in an earlier item, EG confirmed that a Task and Finish Group meeting is in the process of being arranged. Anyone wishing to attend should contact EG or EA. It was noted that DGH representatives would be helpful. Post meeting note: JL and MW agreed to sit on this group. 	All
	<ul style="list-style-type: none"> • Costings data from Leeds JL is looking at costings and awaiting receipt of clean data after which she will forward to EG. 	JL
14.	<p>Parent and carer support groups and engagement - progress report (CM/SS) Due to the summer break, there is nothing to report. It was suggested that it would be useful to feed back to Parent and Carer Groups information from other meetings.</p>	All
15.	<p>Any other business</p> <ul style="list-style-type: none"> • KP informed colleagues that the Programme of Care Lead, NHS England had sent through a spreadsheet for completion with regard to funding provided by CCGs and Specialist Commissioning. KP asked AC to complete the outstanding information on behalf of Sheffield and return to her. • The Group were informed that the National NCePOD document is due to be published in November and, if available in time, the outcome will be discussed at the next meeting. 	Admin
16.	<p>Date and time of next meeting</p> <ul style="list-style-type: none"> • Tuesday 10 December 2019, 10am – 12noon, Cedar Court Hotel, Wakefield. • March 2020 – date to be confirmed and circulated shortly. 	Admin EA/Admin