

YORKSHIRE & HUMBER LONG TERM VENTILATION WORKING GROUP

Date & time	Tuesday 4 February 2020, 10 am – 12 noon
Venue	Annabel Suite, Hatfeild Hall, Normanton Golf Club, Wakefield
Chair	Sian Cooper, Clinical Lead (North), Yorkshire & Humber Paediatric Critical Care ODN

Attendance	
Name	Role & Organisation
Emma Andrews	Network Manager, Yorkshire & Humber Paediatric Critical Care ODN
Andrea Bliss	Associate Director of Nursing from Interim Head of Nursing, 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
Emma Green	Service Specialist, North England Specialist Commissioning Team
Heidi Reynolds	Paediatric Respiratory Physiotherapist, Bradford
Jill Morris	Physiotherapy, Bradford
Karen Perring	Lead Nurse, Y&H Paediatric Critical Care ODN
Sarah Georgiades	Team Leader Children's Nurse Specialist, Leeds Children's Hospital
Carolyn Maundrill	Continuing Care Co-ordinator for Critical Care, Sheffield Children's Hospital
Martin Quinton	Critical Care Practitioner, Sheffield Children's Hospital
Sharon Sloan	Children's Nurse Specialist, Leeds Children's Hospital
Paula Graham	Community Nurse
Kathryn Reeves	Physiotherapist, Leeds Children's
Saikiran Gopalakaje	Consultant Respiratory Paediatrician, Leeds Children's Hospital

Apologies	
Name	Role & Organisation
Haji Sheeraz-Khan	Respiratory Consultant, Hull University Teaching Hospitals
Kelecho Ugonna	Consultant in Paediatric Respiratory Medicine, SCH
Kathryn Davison	Consultant Paediatrician, Mid Yorkshire Hospitals
Karen Pysden	Consultant Paediatric Neurologist, Leeds Children's Hospital
Vikki McAlpine	Paediatric Manager, NLAG
Shane Atkins	Community Children's Care Assistant, Rotherham
Jo Whiston	Lead Nurse, Embrace
Rachel Fox	Respiratory & CF Lead Nurse, NLAG
Clare Smith	Sheffield Children's Hospital
Dr Gouta	Consultant Paediatrician, Barnsley

		Action
1.	<p>Welcome, apologies and introductions</p> <p>SC welcomed all to the meeting. Introductions were made and apologies recorded above.</p>	
2.	<p>Minutes of the last meetings held 17 June and 3 September 2019</p> <p>The minutes of the last meeting were agreed as an accurate record.</p>	
3.	<p>Agreed actions 3 September 2019 (EA)</p> <ul style="list-style-type: none"> Anonymised Leeds costings data sent to EG – JL EG Confirmed this information had been received. More work was required. <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> <ul style="list-style-type: none"> No update available. SC to follow up with Vanessa -aim for draft pathway complete by next meeting. 	SC / VC
5.	<p>Mapping Exercise for Y&H LTV patients (including NIV) and planning for education and training needs</p> <ul style="list-style-type: none"> VC meeting teams (medical) KP has looked at Leeds/Sheffield data VC & KP have met to discuss the information. Each trust has individual education and training needs 4 Hospitals in SY with >10 patients – Barnsley, Doncaster, Rotherham and Chesterfield <p>It was acknowledged that there are challenges across hospitals – staffing, no of machines and the ability to maintain competencies. Training needs to continue to be tailored to each hospital and is provided by the tertiary centre LTV services. Not every hospital will be suitable for providing this level of service.</p> <p>Actions Some of this will be picked up in the Y&H PCC ODN clinical forum on 10/03. Develop Minimum Standard of care for private agencies to support the delivery of consistent and quality services. Need to work with CCGs. EA & EG to consider best way to take this further.</p>	AC/SG EG/EA
6.	<p>Y&H Respiratory Network Meeting 17 January 2020</p> <p>A brief update from the meeting was received. LTV in the context of SMA was discussed Very well attended from a DGH medical workforce perspective.</p>	
7.	<p>Y&H PCC ODN Clinical Forum 10 March 2020 – agenda</p> <p>Request to all in attendance to advertise locally. Agenda is now confirmed and is attached for circulation. 40 already booked to attend.</p>	
8.	<p>Y&H Future Leaders Bid</p> <p>Agree that CE will submit a bid for next year. The dead line has passed for this year.</p>	CE
9.	<p>Online FAQ for parents and carers – progress report</p> <p>No feedback received for this item The FAQ document is complete; however it is not clear where this should be</p>	

		Action
	published. Each unit to look at how to add this document. HK working with IT FAQ to be sent to CE	HK / CE SC
10.	Embrace FAQ list SC to chase up with JOFAQ to be forwarded to LR Discussions around the inclusion of Embrace in emergency working particularly re DGH presentations – Leeds to consider including in guidance – SG This is already undertaken in the South of the patch, all DGHs request an Embrace transfer to SCH.	SC JO SG
11.	Commissioning Task and Finish Group A paper was taken to the Children’s Hospital Partnership Board on Friday 31/01 detailing the progress made by both this group and the commissioning Task and Finish Group. It was well received and the board were pleased with the progress being made. The paper explained the issues/barriers/solutions 5 work streams have been developed 1. Acute pathway 2. Prevention – reduction of admissions/working with community services 3. Discharge planning/LTV stepdown – clear understanding of discharge processes and barriers 4. Honorary Contracts 5. LTV specific care areas including the services required – may include DGHs Oversight and accountability Not all of the work streams are the responsibility of this group, some of the responsibility sits with commissioning/CCG. The aim of the Task and Finish group was to involve the relevant stakeholders outside of this group, as well as within the group, in being able to action the changes needed to solve some of the problems identified in the patient pathway. . Need to meet as the Task and Finish group again to seek ownership and then seek volunteers. The Children’s Hospital Partnership Board will continue to seek updates and will hold to account for responsibility. This work stream also sits on the PCCODN executive board agenda	EG/EA
12.	Parent and carer support group and engagement - update SCH <ul style="list-style-type: none"> training days being run in May for carers regional training workshops for parents – drop in basis format – coffee morning with ventilators and resus training Leeds <ul style="list-style-type: none"> BLS drop in being offered Feedback from families re current system – being fed back to the working group Bradford <ul style="list-style-type: none"> Auditing NIV Includes family feedback Also including transition SC will draft letter that can be given to families regarding the progress of this group based upon their feedback and focus group attendance so far	SC
13.	Review Terms of Reference Jan 2019 Update executive lead – amend to read Spec Comm Invite a representative from ED and Anaesthetics to contribute to acute pathway	SC

		Action
	<p>work</p> <p>Change frequency of the meetings to 6 monthly</p> <p>Task and Finish Groups will be established for each work stream the line of accountability will either be to this group for the works teams relevant to spec comm.</p> <p>Need to consider what the line of accountability is for the work streams which sit within CCG commissioning.</p>	
14.	<p>Any other business</p> <ul style="list-style-type: none"> • CE encouraging to see the profile of LTV being raised in multiple forums • MQ SCH are working with InterSurgical to save money – agreed to share outcomes with LCH • AC Nasopharyngeal Suction. This is an ongoing community in the south of the patch. In Leeds training is given to parents not carers as agencies class as deep suction. One agency did agree on a case by case basis. • Bradford have a written policy around this. HR to send to SC for dissemination. 	HR/SC
15.	<p>Date and time of next meeting</p> <p>Wednesday 9 September 2020, 10-12am,</p>	

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