

## YORKSHIRE & HUMBER LONG TERM VENTILATION WORKING GROUP

### Notes & Actions

<b>Date and time</b>	Wednesday 9 January 2019 10:00 – 12:00
<b>Venue</b>	Hatfeild Hall, Aberford Road, Wakefield, WF3 4JP
<b>Chair</b>	Sian Cooper, Clinical Lead (North), Yorkshire & Humber Paediatric Critical Care ODN

Attendance	
Name	Role & Organisation
Sian Cooper	Clinical Lead (North), Yorkshire & Humber Paediatric Critical Care ODN
Karen Perring	Lead Nurse, Yorkshire & Humber Paediatric Critical Care ODN
Emma Andrews	Network Manager, Yorkshire & Humber Paediatric Critical Care ODN
Anne-Marie Childs	Consultant Paediatric Neurologist, Leeds Children's Hospital
Stuart Conquer	Principal Physiotherapist in Respiratory Care, Sheffield Children's
Chris Edwards	Consultant Respiratory Paediatrician, Leeds Children's Hospital
Sarah Georgiades	Team Leader Children's Nurse Specialist, Leeds Children's Hospital
Kiran Gopalakaje	Consultant Respiratory Paediatrician, Leeds Children's Hospital
Emma Green	Service Specialist, North England Specialist Commissioning Team
Diarmuid Kerrin	Consultant Paediatrician, Barnsley
Mathew Kurian	Consultant Paediatrician, Doncaster & Bassetlaw
Jo Lumsden	Consultant Paediatric Intensivist, Leeds Children's Hospital
Carolyn Maundrill	Continuing Care Co-ordinator for Critical Care, Sheffield Children's Hospital
Eduardo Moya	Consultant Paediatrician, Bradford
Karen Pysden	Consultant Paediatric Neurologist, Leeds Children's Hospital
Claire McClean	Clinical Educator, Embrace Transport Service
Jo Whiston	Lead Nurse, Embrace Transport Service
Joanne Reed	Clinical Nurse Manager, Paediatrics, Calderdale
Kathryn Reeves	Highly Specialised Paediatric Respiratory Physiotherapist, Leeds
Lee Richardson	Clinical Nurse Ventilation Specialist, Sheffield Children's Hospital
Caroline Savage	Senior Staff Nurse, Paediatric High Dependency Unit, Hull
Anil Shenoy	Consultant Paediatrician, Bradford
Clare Smith	Continuing Care Co-ordinator, Rotherham
Rum Thomas	Consultant Paediatric Intensivist, Sheffield Children's Hospital
Kelechi Ugonna	Consultant Respiratory Paediatrician, Sheffield Children's Hospital
Murray Wheeler	Consultant Paediatrician, York
Shane Atkins	Community Children's Care Practitioner, Rotherham
Karen Pattrick	Senior Staff Nurse, Paediatric High Dependency Unit, Hull

Apologies	
Name	Role & Organisation
Debbie Bray	Deputy Head of Nursing (Children), North Lincolnshire & Goole
Amika Challacombe	Clinical Nurse Ventilation Specialist, Sheffield Children's Hospital
Kathryn Davison	Consultant Paediatrician, Mid Yorkshire Hospitals
Anna Linden	Consultant Paediatrician, Harrogate
Jess Oldfield	Transport Consultant and E-MAP lead, Embrace Transport Service
Min Ong	Consultant Paediatric Neurologist, Sheffield Children's Hospital
Kay Rushforth	Head of Nursing, Children's Services, Bradford
Lauren Williams	Physiotherapist, Sheffield Children's Hospital
Sharon Hodgson	Programme of Care Lead for Women and Children, NHS England

	Agenda Items	Lead
1.	<b>Welcome, apologies and introductions</b>	
2.	<p><b>Introduction and aims</b></p> <p>The aim of this group was described as seeking to deliver consistency of services across the region, referring to the NHSE PCC Review – “high quality care as close to home as possible”. In addition to try and develop relationships and working together across the region</p>	
3.	<p><b>Terms of reference</b></p> <p>The group discussed the draft terms of reference which had been circulated in advance of the meeting.</p> <p>The group discussed the importance of ensuring relevant groups were represented and that other organisations are kept up to date. Some of the commissioning of services for LTV falls outside of the remit of this group and it is important to keep commissioners within STP footprints up to date with any actions.</p> <p>Need to include representatives form Allied Health Professionals (Speech and Language/OT). Also given the challenges around discharge should Social Care be involved? It was agreed that this would be pursued further.</p> <p>The group agreed the expectation that if you are representing your organisation at this meeting it is your responsibility to disseminate information.</p> <p>Communication – the group agreed that emailing links to the website and the website having an established LTV area for relevant documentation would be helpful.</p> <p>TOR are to be reviewed annually.</p> <p>Definition of LTV – needs to include invasive and non-invasive ventilation. Anyone requiring respiratory support for 4 months.</p> <p>The following actions were agreed:</p> <ul style="list-style-type: none"> <li>• Approach Sarah Halstead to be Senior Level Lead and link to commissioners</li> <li>• Include the NIC ODN and Palliative Care Network</li> <li>• Establish Focus Groups to deliver patient/parent engagement – small group to be established to progress this work</li> <li>• Contact Children's Services Leads in Sheffield and Leeds for representatives</li> </ul>	EA SC RT  SC
4.	<p><b>What is working well in the region, and why?</b></p> <p><b>Sheffield</b></p> <p>Has a continuing care discharge coordinator which has proved to very successful, since 2012.</p>	

The following data was presented:

Tracheostomy Ventilated Bed Days since 12/13 financial years.

Year	No of Pati	Bed Days	Bed Days Fit for Discharge
12/13	8	1258	938
13/14	9	972	482
14/15	9	1134	576
15/16	7	1031	230
16/17	9	1517	723
17/18	4	327	222

The spectrum of diagnoses are changing, an increase in tracheobronchio malacia and a reduction in neuromuscular.

It was reported that for children with chronic lung disease, more patients are managing to get home on low flow.

The service across Sheffield is well resourced and well established. It has 3 consultants, running 3 clinics per week for LTV and 1 MDT meeting weekly. This is also supported by an LTV nursing team which includes a well child nurse.

The trust has an excellent Sleep Service which helps identify LTV patients.

Treatment is often established in the community.

#### **Leeds**

Data wasn't available at the meeting, however on average (data to be provided), Leeds receives 15 new referrals per year, equating to around 85 children. Over the past 5 years LTV patients have utilised around 3060 bed days equating to £6,000 000 for the bed alone.

There are 85 patients on NIV or have a tracheostomy.

Clinicians from Leeds felt that the service was around 5 years behind Sheffield in terms of being able to proactively identify patients, due to their development of the sleep service.

#### **Calderdale and Huddersfield**

Calderdale have developed a clear process in partnership with HR for allowing carers to accompany children to hospital and to allow them to care for them. This is by way of honorary contracts.

Sheffield have developed an NIV pathway – this was agreed to be shared

#### **5. What is not working well in the region, and why?**

The group acknowledged the significant difference between services delivered in Leeds and Sheffield NHS FTs

Staff in the district generals felt that early communication regarding patients who will end up in their service would be useful.

There is difficulty in maintaining competencies for staff in the DGHs and often the DGH is not aware of the care agreed for the child.

There is no consistency around the approach to having carers in hospital – different agencies have different rules.

The group discussed what patients would be suitable for admission to a DGH. MW suggested that it might be useful to define levels of care to assist in defining where patients should go for the most appropriate treatment/care.

Due to care plans and pathways of care being developed predominantly with the tertiary units, these are not always available to the DGH consultants upon admission.

There is a difference across the region in terms of admission policy. Sheffield – LTV patients arriving at a local ED are stabilised only and then transferred to SCH for ongoing care in the majority of cases. In Leeds, DGHs are encouraged to admit children and keep them for 24 hours or sometimes longer.

<b>6.</b>	<b>Prioritising work to be done</b> See Attached Action Plan	
<b>7.</b>	<b>Volunteers</b> See attached Action Plan	
<b>8.</b>	<b>Action plan</b> Attached	
<b>9.</b>	<b>Any other business</b> <b>No items raised</b>	
<b>10.</b>	<b>Date and time of next meeting</b> 26 <sup>th</sup> March 2019 12-2pm Hatfeild Hall, WF3 4JP	

## Agreed Actions 9 January 2019

	<b>Actions</b>	<b>Lead</b>	<b>Timeline</b>
1.	Amend Terms of Reference and send to group for final comment	Sian Cooper	January 2019
2.	Parent and carer engagement - set up LTV focus group and report on progress at next meeting	Rum Thomas	April 2019
3.	Progress the business case for LTV service in Leeds for West Yorkshire & Humber patients - report on progress at next meeting	Chris Edwards	April 2019
4.	Share with Leeds and Hull the Sheffield Children's Hospital pathway for acute admission of LTV patients	Stuart Conquer	January 2019
5.	Mapping exercise to give clear idea of numbers of patients receiving LTV support (including non-invasive support) in Y&H and the regional distribution	Sarah Georgiades / Lee Richardson	April 2019
6.	Subgroup to look at the pathways for LTV patients who are acutely unwell or injured. To consider: <ul style="list-style-type: none"> <li>• Admission for acute respiratory illness</li> <li>• Admission for other illness or injury</li> <li>• Mechanisms for providing advice - who, when, how</li> <li>• Thresholds for transfer to both tertiary centres</li> <li>• Existing resources in both tertiary centres</li> </ul> Expressions of interest to be involved in this work to SC	Sian Cooper	April 2019
7.	Collate list of items (eg. LTV, neuromuscular disease) for which we would like to agree minimum acceptable standards of care against service specifications, national standards etc. Individual specialists to send to SC and copy in relevant colleagues to avoid duplication of work.	Sian Cooper	April 2019
8.	Conversation with Specialist Commissioning regarding joined up working, LTV funding, specialist commissioning, CCGs and engaging with ongoing STP / ICS work - report back to group at next meeting	Emma Andrews / Emma Green	April 2019
9.	Collate pathways and guidelines already available within Y&H and other regions	Karen Perring	April 2019
10.	Data from both Paediatric Critical Care Units on LTV patient numbers past 5 years including those being cared for in a level 3 critical care bed who are medically fit for discharge	Carolyn Maundrill / Jo Lumsden	April 2019
11.	For the agenda next time: <ul style="list-style-type: none"> <li>• Training packages and getting home</li> <li>• Feeding</li> </ul>	Sian Cooper	April 2019
12.	Doodle Poll for next meeting in 3 months April 2019	Sian Cooper	January 2019