

YORKSHIRE & HUMBER LONG TERM VENTILATION WORKING GROUP

DRAFT Notes & Actions

Date and time	Tuesday 26 March 2019 12:00 – 14:00
Venue	Hatfeild Hall, Aberford Road, Wakefield, WF3 4JP
Chair	Sian Cooper, Clinical Lead (North), Y&H Paediatric Critical Care ODN

Attendance	
Name	Role & Organisation
Amika Challacombe	Clinical Nurse Ventilation Specialist, Sheffield Children's Hospital
Sarah Cockroft	Practice Educator, Martin House Children's Hospice
Sian Cooper	Clinical Lead (North), Yorkshire & Humber Paediatric Critical Care ODN
Ann Donkin	ODN Information Support Officer
Chris Edwards	Consultant Respiratory Paediatrician, Leeds Children's Hospital
Sarah Georgiades	Team Leader Children's Nurse Specialist, Leeds Children's Hospital
Paula Graham	Children's Nurse, Barnsley Hospital
Emma Green	Service Specialist, North England Specialist Commissioning Team
Davina Hartley	Y&H Paediatric Palliative Care Network Manager
Hemant Kulkarni	Consultant Respiratory Paediatrician, Sheffield Children's Hospital
Carolyn Maundrill	Continuing Care Co-ordinator for Critical Care, Sheffield Children's Hospital
Jess Oldfield	Transport Consultant and E-MAP lead, Embrace Transport Service
Karen Pattrick	Senior Staff Nurse, High Dependency Unit, Hull
Karen Perring	Lead Nurse, Yorkshire & Humber Paediatric Critical Care ODN
Kathryn Reeves	Highly Specialised Paediatric Respiratory Physiotherapist, Leeds
Lee Richardson	Clinical Nurse Ventilation Specialist, Sheffield Children's Hospital
Kay Rushforth	Head of Nursing, Children's Services, Bradford
Caroline Savage	Senior Staff Nurse, Paediatric High Dependency Unit, Hull
Anil Shenoy	Consultant Paediatrician, Bradford
Sharon Sloan	Children's Nurse Specialist, Leeds Children's Hospital

Apologies	
Name	Role & Organisation
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
Sarah Halstead	Senior 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
Anton Mayer	Consultant in Palliative Care, Sheffield Children's Hospital
Eduardo Moya	Consultant Paediatrician, Bradford

Min Ong	Consultant Paediatric Neurologist, Sheffield Children's Hospital
Karen Pysden	Consultant Paediatric Neurologist, Leeds Children's Hospital
Martin Quinton	Operating Department Practitioner, Sheffield Children's Hospital
Joanne Reed	Clinical Nurse Manager, Paediatrics, Calderdale
Rum Thomas	Consultant Paediatric Intensivist, Sheffield Children's Hospital
Kelechi Ugonna	Consultant Respiratory Paediatrician, Sheffield Children's Hospital
Vicky Watson	Speech and Language Therapist, Leeds Children's Hospital
Jo Whiston	Lead Nurse, Embrace Transport Service

	Agenda Items	Lead
1.	Welcome, apologies and introductions	
2.	Minutes of last meeting 9 January 2019 - agreed	
3.	Agreed actions 9 January 2019 <ul style="list-style-type: none"> • Terms of reference amended and agreed • NIV guideline for acute admission SCH shared with Leeds/ Hull by Stuart Conquer • All other actions listed as separate agenda items 	
4.	Parent and carer engagement – focus groups Both Sheffield and Leeds LTV services have held a parent / carer focus group as an action from the first meeting. SG and CM presented the themes. It was agreed to send the full notes from each focus group to the members of the LTV working group for information. Themes from the focus group in Leeds (5 families): Aspirations for general support and advice <ul style="list-style-type: none"> • Telephone advice out of hours from the LTV team • Psychological support and sibling support accessed at home or in hospital • Social media support group to include health care professionals Positive comments about transition to home: <ul style="list-style-type: none"> • Availability of a step-down facility for Leeds children to reduce time in hospital • Availability of LTV outreach team for short term use Community care teams, equipment and training <ul style="list-style-type: none"> • All families would like higher quality suction machines • Adaptations should be standardised across the region according to best practice • Variable quality of care across agencies and teams • Absence of community physiotherapy service unless living in Bradford • More support is required for training in schools • Additional basic life support training for parents would be useful Experiences of acute illness or injury: <ul style="list-style-type: none"> • LTV specialist nurses valued as the first point of call and for facilitation of admission, liaising with PICU and reducing time spent in emergency department • If advice is sought from PICU staff, this is not always appropriate • Families would prefer to stay at home when their child is unwell, but to achieve this would need physiotherapy and LTV nurse support with home visits • DGH staff are perceived as being “scared” to look after LTV patients when they are acutely unwell, and they do not always have the skills or experience to do so • Would like a dedicated LTV unit with specialised staff who are experienced in looking after children on ventilators, open to children from across the region • Poor experiences and long waits in emergency departments and acute 	SC

	<p>assessment wards, at DGH and in Leeds</p> <ul style="list-style-type: none"> • Community care teams should to be able to go with their child into hospital for planned procedures and acute illness, to maintain familiarity and continuity of care <p>Themes from the focus group in Sheffield (9 families): Many of the themes were similar, but in addition: General support and advice:</p> <ul style="list-style-type: none"> • More psychosocial preparation for home life and how to cope • Would like 24/7 phone support and acute care plan for every child • Request for refresher / training group as means of peer / professional support • Would like lead consultant paediatrician as point of contact in Sheffield <p>Comments about transition to home:</p> <ul style="list-style-type: none"> • HDU not the right environment, too medicalised, would like step-down facility / LTV unit • High quality of training in preparation for discharge • Delays in home adaptations / rehousing <p>Community care teams, equipment and training:</p> <ul style="list-style-type: none"> • Debate about continuing care teams versus agencies. Pros and cons of both. • Personal health budgets working quite well for some. • Spoke highly of respiratory community team, but only available 9-5 Mon-Fri • More support for schooling <p>Experiences of acute illness or injury:</p> <ul style="list-style-type: none"> • Praise for some of the local paediatricians with respiratory interest • Some would like to bypass their local hospital and go straight to Sheffield • Would like more training for local hospitals • Poor experiences and long waits in emergency departments and acute assessment wards, at DGH and in Sheffield • Want to raise awareness for professionals about QoL and abilities of children and young people who are technology dependent. <p>Both SG and CM felt that Both felt that it was important to feed back to families the impact of their engagement in terms of what the LTV group is trying to do and the influence their comments had - such as the work to be done on the acute pathway.</p> <p>Request for ambulance service to be able to “flag” NIV patients – SC to investigate.</p> <p>Leeds felt that they did want to have a local parent support group supported by professionals to include social media, which Sharon Sloan will lead. They felt that future engagement should involve a wider range of families.</p> <p>Sheffield didn’t feel the need for a support group, but CM will look into the logistics of developing a regular refresher / training session for families.</p> <p>We agreed to keep "parents and carer support groups and engagement" on the agenda.</p>	<p>SC</p> <p>SS</p> <p>CM</p> <p>RT</p>
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<p>5.</p>	<p>Mapping exercise for Y&H LTV patients (including NIV)</p> <p>a) Data from West Yorkshire presented – totals as of March 2019 are 59 NIV, 21 tracheostomy, 80 children in total. Regional breakdown of 22 in Leeds area and the rest (58) spread across the region. Number of new referrals by region over past 7 years also presented, showing a rise in NIV referrals with tracheostomy referrals remaining static.</p> <p>b) Data from South Yorkshire – 125 NIV, 31 tracheostomy, 156 total. Regional breakdown of 50 in Sheffield area and 75 outlying areas, including as far as Lincoln and Boston. Lee Richardson to send the SY breakdown to SC.</p> <table border="1" data-bbox="304 450 1238 568"> <thead> <tr> <th></th> <th>Age</th> <th>NIV</th> <th>Trach</th> <th>Total</th> </tr> </thead> <tbody> <tr> <td>West Yorkshire / Leeds</td> <td><16</td> <td>59</td> <td>21</td> <td>80</td> </tr> <tr> <td>South Yorkshire / Sheffield</td> <td><18</td> <td>125</td> <td>31</td> <td>156</td> </tr> </tbody> </table> <p>Two things are notable:</p> <ol style="list-style-type: none"> 1. The population of West Yorkshire is larger than that of South Yorkshire 2. Sheffield includes data on children until their 18th birthday whereas Leeds uses 16th birthday as the cut-off before transition to adult services. <p>National LTV NCEPOD study</p> <p>Karen Perring raised this in connection with the National PIC Review as part of a subgroup looking at LTV. Chris Edwards is involved as a case reviewer for the NCEPOD study and explained more about the work – planned to be published Nov 2019. NCEPOD champion in each trust. NCEPOD LTV study being led by adult anaesthetist. Project is not running to schedule because of problems in getting hold of notes for case reviewers. Aims are:</p> <ul style="list-style-type: none"> • To scope numbers of patients nationally • To carry out case review on selected patients • To issues questionnaires on service and case management • To involve patients and families <p>The hope is that the output of the NCEPOD study will feed into the NHSE recommendations for LTV. The group agreed that it is still important to focus on the issues in Y&H and to have knowledge of the local data and work on improving pathways in this group. We will await the outcome of the NCEPOD study.</p>		Age	NIV	Trach	Total	West Yorkshire / Leeds	<16	59	21	80	South Yorkshire / Sheffield	<18	125	31	156	<p>LR</p>
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<p>6.</p>	<p>5 year data from Leeds and Sheffield critical care units</p> <p>CM presented data from Sheffield at the last meeting (LTV bed days / bed days fit for discharge from PICU over last 5 years). JL sent apologies – to update regarding Leeds data at next meeting.</p>	<p>JL</p>															
<p>7.</p>	<p>Minimum acceptable standards of care – list of items</p> <p>The West Midlands Quality Review Service (WMQRS) Quality Standards published April 2015 are accepted by all as the national standard of care for LTV services. It is consistent with the NHSE LTV service specification.</p> <p>An update on update on standards of care recommendations for Spinal Muscular Atrophy 2017 exists as a position statement on management at the current time.</p> <p>The 2018 Ray et al document on developing an ethical framework for decision making was discussed briefly and the Leeds team will review their current process regarding this.</p>	<p>CE</p>															
<p>8.</p>	<p>Pathways for LTV patients who are acutely unwell or injured</p> <p>This is identified as a priority for both DGH teams and families. Volunteers for this work (JO, KU, AMC, CE, RT) but in need of DGH representation. Volunteers to SC please.</p>																

9.	<p>Pathways and guidelines already available</p> <p>The West Midlands Quality Review Service (WMQRS) Quality Standards are accepted as the national standard of care for LTV services. It is noted that there is no specific guidance on acute illness or injury pathways.</p>	
10.	<p>Nutrition, training packages and getting home</p> <p>No-one was available to discuss any issues regarding nutrition.</p> <p>Training packages were discussed. LR and AC carry out ongoing training including basic life support (BLS) in the South; this is done by carers in the West.</p> <p>West Yorkshire run a monthly regional workshop for agencies / ward staff / schools / community staff.</p> <p>Chris Edwards wondered if a Leadership Fellow could be utilised to develop a Y&H wide online training package? He will investigate.</p>	CE
11.	<p>Business case for LTV in Leeds for West Yorkshire</p> <p>There has been no significant expansion in consultant or nursing support for over 10 years. Management support is positive, with a designated area planned in the new build, but no definite commitment with the current business case still awaiting signoff.</p> <p>Previous business cases have not been approved. The bid includes consultant SPA time, nursing, admin, physiotherapy, speech and language, play therapy and psychology support for the LTV service.</p> <p>The group agreed to write from the PCCODN expressing support for the bid (enclosing feedback from the parent focus group) and to send the minutes of this meeting to Suzanne Abrahams, Business Manager for LCH.</p>	SC
12.	<p>Update on commissioning discussions</p> <p>Emma Green from specialised commissioning is liaising with Leeds CCG to understand the issues and barriers in terms of commissioning. Davina Hartley suggested that she may be able to help in terms of the Palliative Care Network and their relationship with the ICS / STP. Emma Green asked for some more clarity on the issues that need to be resolved in respect to PIC capacity and discharge home / acute illness pathway. SC / CM / SG to contact Emma separately regarding key issues and impact.</p>	SC / CM / SG
13.	<p>Any other business</p> <p>Discussed again the issue of community carers having honorary contracts to be able to care for LTV patients admitted to their DGH. SC to contact Joanne Reed in Calderdale for HR paperwork / process used there.</p> <p>Chris Edwards to offer educational session to ED in Leeds regarding LTV / technology dependent children</p> <p>Chris Edwards to investigate regarding setting up FAQ online for parents and carers</p> <p>Flyer to be circulated for West Midlands LTV Network 25 June 2019</p> <p>No neonatal representative yet identified on the group – SC to chase up</p>	<p>SC</p> <p>CE</p> <p>CE</p> <p>KP</p> <p>SC</p>
14.	<p>Date and time of next meeting – June 2019 TBC via Doodle Poll</p>	

Agreed Actions 26 March 2019

	Actions	Lead	Timeline
1.	Parent and carer support groups and engagement – report on progress from Leeds and Sheffield at next meeting, and keep on agenda as rolling item	Rum Thomas Caz Maundrill Sharon Sloan	June 2019
2.	Circulate minutes from initial parent and carer focus groups to the LTV working group for information (NOT for website)	Sian Cooper	April 2019
3.	Data from Sheffield mapping exercise on whole numbers of LTV patients (NIV and tracheostomy) including breakdown of DGH patients to be sent to SC	Lee Richardson	April 2019
4.	Data from Leeds PICU 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	Jo Lumsden	June 2019
5.	Acute pathway subgroup to look at whole pathway in Y&H for all LTV patients (NIV and tracheostomy) when acutely unwell or injured. More representation needed (including DGH) and one or two to lead the group. Volunteers to SC please.	Not yet named	April 2019
6.	Contact ambulance service to ask if could add “flag” on system for NIV patients as currently exists for tracheostomy patients	Sian Cooper	June 2019
7.	Offer educational session to Emergency Department in Leeds regarding LTV patients	Chris Edwards	June 2019
8.	Ethical framework for decision making in LTV – Leeds team to review current process and consider how it could be strengthened	Chris Edwards	June 2019
9.	Idea to develop online FAQ for parents and carers in the absence of 24/7 phone advice. CE to look into logistics and governance of doing this and report back at next meeting	Chris Edwards	June 2019
10.	Support for LTV business case in Leeds for West Yorkshire & Humber – (1) letter to Suzanne Abrahams from SC / KP on behalf of ODN summarising LTV parent focus group views and (2) minutes of this meeting to be sent to Suzanne Abrahams	Sian Cooper	April 2019
11.	Commissioning – email Emma Green setting out key issues and impact of commissioning barriers for LTV on children and families (CM/SG) and on PIC capacity (SC)	Caz Maundrill Sarah Georgiades Sian Cooper	April 2019
12.	Contact JR in Calderdale regarding carers / honorary contracts	Sian Cooper	April 2019
13.	Midlands Children’s LTV network conference flyer 25/6/19 at St Georges Hospital, Stafford to be sent to group	Karen Perring	April 2019
14.	Neonatal representative on group	Sian Cooper	April 2019
15.	Doodle Poll for next meeting in 3 months June 2019	Sian Cooper	April 2019