

**North West ODN Oversight Group for Paediatric Long Term Ventilation**

9<sup>th</sup> December 2022 13:00-15:00 Via MS Teams

**MINUTES**

Item	Actions
<p><b>1. Welcome and Introductions</b></p> <p>Joanna McBride welcomed attendees to the meeting.</p> <p>For attendance and apologies, please see appendix 1.</p>	
<p><b>2. Minutes of last meeting</b></p> <p>Minutes agreed.</p> <p>Next steps from last meeting:</p> <ul style="list-style-type: none"> <li>- Audit of care packages – to see what families are getting – on agenda</li> <li>- Work to look at why carers are leaving</li> <li>- Work with NHSE to get issues discussed today escalated</li> <li>- Work with hospices to look at intermediate care – on agenda</li> <li>- Cost of living crisis and the impact on LTV families – leaflet circulated</li> <li>- Work with WellChild to ensure we have parental and family involvement – in progress</li> <li>- Finalise Terms of Reference – on agenda</li> </ul>	
<p><b>3. Review of patient numbers</b></p> <p>AHCH</p> <ul style="list-style-type: none"> <li>- Numbers are pretty static</li> <li>- 150 patients in total; 26 IV and 124 NIV</li> <li>- 2 transitioning, 1 going home on Monday</li> <li>- 1 new set up for NIV</li> <li>- 1 NIV pt on HDU</li> <li>- 3 children acutely unwell on NIV, having to be nursed on ward, due to PICU pressures</li> </ul> <p>RMCH</p> <ul style="list-style-type: none"> <li>- 125 patients in total; 91 NIV and 34 IV</li> <li>- Busy from inpatient point of view; 11 patients in, mix of IV and NIV</li> <li>- 2 children on PICU</li> <li>- 9 children stable over 90 days totalling 3026 bed days (data submit to NHSE data portal)</li> <li>- Starting new children on LTV, so numbers will go up by 2 from next week</li> </ul> <p>With regards to data, Elaine explained that there are to be 4 new codes introduced for LTV, so it should become possible for the business intelligence systems to pick up LTV children and therefore we should be able to track patients with more ease.</p>	

#### 4. Update of workplan, workstreams and working groups

Presentation given by Jo McBride:



Year 2 priorities  
12.11.2022 LTV.docx

With regards to the standards, permission is being sought to share the West Midlands standards. The standards will be circulated to this group when the permission has been obtained, with a view for us to agree to adopt them. The standards will then be used to develop a peer review for the North West.

#### 5. Level 2 bed – service development planning

Presentation given by Jo McBride:



LTV oversight L2  
SDF 9.12.22.pptx

#### 6. Updates – Local teams and linked networks

LTV Nurses sub-group

- Ongoing issues with tracheostomies and consumables being in short supply
- Representation from Philips and Breas at last meeting which was helpful to update the group
- Breas cough assist has a 24 week lead time currently
- Water shortages for humidifiers
- Changing equipment around to unfamiliar equipment increases risk to patients at home

RMCH

- Now have stock of A40 ventilators from Philips, but now no longer have the bed to use for changing the patients over. Will try and do as many patients as possible in clinic. But whole process will now take longer.
- Issues with delayed discharges, but working hard to try and get the children out early in the new year

AHCH

- 2 IV patients and 4 NIV patients currently in – care packages going well, just waiting for 1 to be set up now
- Issues with care packages breaking down in community, more so in Wales where there is no hospice support
- Same issues with tracheostomies

Hospices

- Issues keeping staff updated with training, as the tracheostomy tubes aren't getting changed as often
- Elaine noted that the simulation dolls when purchased will help with training
- At recent meeting with hospices, the consensus was that hospices may be able to help with some day support at present, but not nights. This will help with training and getting to know the children earlier on in the pathway.

## WellChild

- Have moved offices
- Busy time across programmes
- Had a recent call out for 'better at home' applications
- Looking to put in a few more training suites before the end of the financial year
- Will share outcome of where these will be when decided
- Re cost of living, have shared resources available and continue to update this
- Following information re power cuts, lots of families registering for national grid priority list
- Have some access to one off cost of living grants, which can be accessed by families experiencing financial hardship and with a child on life sustaining equipment at home (must be on means tested benefits)
- Going into new year will have a focus on mental health and PTSD for families. Setting up webinars to support parents and siblings.
- Have toy drives running for Christmas, free tickets to activities etc
- Had recent meeting to get WellChild nurses together
- Looking to add a few more additional WellChild nurse posts
- Elaine and Amy to meet to discuss parental involvement in the ODN


## NHS England


- Chasing up getting the Level 2 letters out
- Had session recently looking at LTV as part of the transformation programme, to try and unpick issues and improve pathway. Next stage is to get clinical input.
- System under a lot of pressure at present, so frequent meetings happening to discuss this

## Care package audit summary:

Package	Alder Hey	Royal Manchester Childrens	Overall
Total Number of Packages	25	39	64
Inpatients awaiting	3 (12%)	8 (21%)	11 (17%)
Number of children in the community	22 (88%)	31 (79%)	53 (83%)
Recent discharges before full package 20-30 hours short		2 (6%)	2/53 (4%)
Full Compliment	9 (41%)	13 (42%)	22/53 (41%)
Residential	1 (5%)		1 (2%)
Shortages of less 20 hours or more /two nights	8 (36%)	6 (19%)	14 (26%)
Shortages of more than 20 hours /2 nights on a regular basis	4 (18%)	5 (16%)	9 (17%)
Chosen to have no package		2 (6%)	2 (4%)
PHB with budget rather than hour allowance		1 (3%)	1 (2%)
Uncontactable		2 (6%)	2 (4%)

- Elaine talked through the summary table, noting that if we are aiming for packages to be 100% filled on discharged, once children are in the community very few are actually getting 100%
- Hospital beds are being blocked whilst patients are waiting for their care packages to be filled
- WellChild survey showed that parents are struggling with resilience
- Families are struggling with the cost of living, and some are seeking for their children to be admitted. Hopefully the supportive grants will help with this.
- Phil suggested looking into if there are any initiatives within local authorities, as public health is now rooted within local authorities

<p>Equipment and maintenance workstream</p> <ul style="list-style-type: none"> <li>- Starter kit reflective of what is within new West Midlands standards</li> <li>- Manchester maintenance service working well</li> <li>- Alder Hey developing proposal for service to be signed off by ICBs to get commissioned</li> </ul> <p>Training workstream</p> <ul style="list-style-type: none"> <li>- Elaine, Anna and member of VAST team to carry out literature review throughout January</li> <li>- Level 2 monies will fund educators and sim dolls to allow education programme to get going</li> <li>- Pan London competencies are to be looked at with a view to making them a national standard - exemplar competencies</li> </ul> <p>Standards</p> <ul style="list-style-type: none"> <li>- West Midlands standards to be circulated when we have permission</li> <li>- Or it is possible for individuals to request a copy of the standards through the Partners in Paediatrics website <a href="#">Midlands Children's Long Term Ventilation Network (MCLTVN) - Partners in Paediatrics</a></li> </ul>	
<p><b>7. National update</b></p> <p>Item deferred.</p>	
<p><b>8. Risks</b></p> <p>Presentation given by Helen Blakesley:</p>  <p>LTV Risk register.pptx</p> <ul style="list-style-type: none"> <li>- Does risk rating need to be increased re impact to patients of delayed discharges (more so to patients other than the LTV patients on account of current PCC pressures)?</li> <li>- 448 critical care bed days used by 2 LTV patients currently</li> <li>- Group agreed score should be increased to 4</li> <li>- Elaine suggested that the cost of living crisis and power outages is added. Information on this has already been sent to Anthony Prudhoe and Andrew Bibby. Phil Rigby will follow up on this, and add to PoC risk register. Phil commented for the ODN this would be more of an issue to be aware of rather than a risk.</li> <li>- The risk register will go through RMCH, as the host of the ODN.</li> <li>- Phil asked for a separate meeting to be set up between the ODN SLT and Lucy Smeatham and himself to go through the 4 risk registers of the ODN (overall strategic risk register and the registers for each of the 3 arms). Helen will also send the risk registers to Phil and Lucy for them to review prior to the meeting.</li> </ul>	<p>PR</p> <p>HB</p>
<p><b>9. Oversight Group Terms of Reference</b></p> <p>Ratification deferred until next meeting, as meeting not quorate.</p>	
<p><b>10. Moving forward - next steps</b></p> <ul style="list-style-type: none"> <li>- Progressing with the patient and public involvement work with WellChild</li> <li>- Elaine looking to engage individuals to join in on the education workstream</li> <li>- Elaine and Helen to look at who would like to be involved in the risk assessment for care packages work, i.e. to ensure care packages are robust and appropriate</li> </ul>	

<p><b>11. Any other business</b></p> <ul style="list-style-type: none"> <li>- Cost of living support from WellChild: <a href="https://www.wellchild.org.uk/information-category/cost-of-living/">https://www.wellchild.org.uk/information-category/cost-of-living/</a></li> <li>- For info: FAQs from all age continuing care  20221103 AACC Collaborative FAQs (</li> </ul>	
<p><b>12. Education Session - Supporting children into the community</b></p> <p>Deferred until next meeting.</p>	
<p><b>13. Close</b></p> <p>Next meeting:</p> <ul style="list-style-type: none"> <li>• 17<sup>th</sup> March 2023 1-3pm via MS Teams</li> </ul> <p>Upcoming 2023 dates:</p> <ul style="list-style-type: none"> <li>• 16<sup>th</sup> June 2023 1-3pm via MS Teams</li> <li>• 8<sup>th</sup> September 2023 1-3pm via MS Teams</li> <li>• 1<sup>st</sup> December 2023 1-3pm MS Teams</li> </ul>	

**Appendix 1 – Attendance & Apologies:**

**Attendees:**

Network

Joanna McBride, Network Director, NW PCC/SIC/LTV ODN's  
 Elaine O'Brien, Lead Nurse, NW LTV ODN  
 Stuart Wilkinson, Co Clinical Lead, NW LTV ODN  
 Helen Blakesley, Network Manager, NW PCC/SIC/LTV ODN's  
 Louise King, Project Support Officer, NW PCC/SIC/LTV ODN's

Alison O'Leary, WellChild LTV Nurse Specialist, Alder Hey  
 Amy Mitchell, Director of Programmes, WellChild  
 Ania Wasielewska, NHSE  
 Anna Hughes, ANP for LTV, RMCH  
 Flo Bergquist, Parent Educator Nurse Specialist, Alder Hey  
 Michelle Wright, Head of Care, Zoe's Place Baby Hospice  
 Phil Rigby, W&Cs Service Specialist, NHSE NW

**Apologies:**

Clare Halfhide, Lynda Brook, Soraya Begum, Tracy Rawlings, Lesley Anderson-Hadley, Linda Partridge