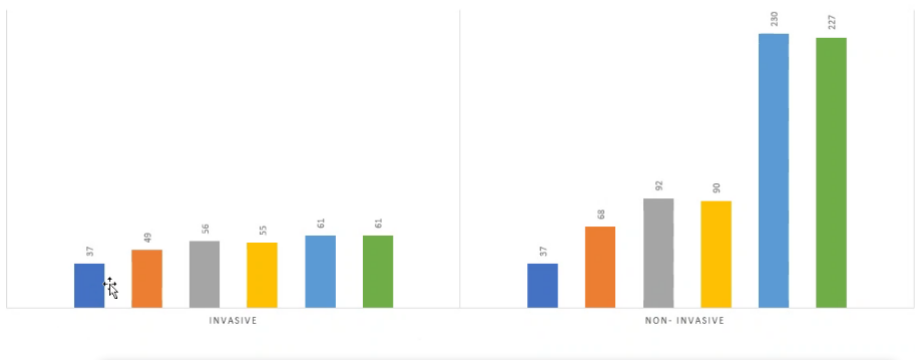



North West ODN Oversight Group for Paediatric Long Term Ventilation

17th March 2023 13:00-15:00 Via MS Teams

MINUTES

Item	Actions																					
<p>1. Welcome and Introductions</p> <p>Joanna McBride welcomed attendees to the meeting.</p> <p>For attendance and apologies, pleased see appendix 1.</p>																						
<p>2. Minutes of last meeting</p> <p>Previous minutes shared for information and agreed.</p>																						
<p>3. Review of patient numbers</p> <p align="center">Total Children on LTV in region 338</p> <div data-bbox="199 1108 1117 1534" style="text-align: center;"> <p>NW PATIENT NUMBERS 2006-2022</p>  <table border="1" style="margin-left: auto; margin-right: auto;"> <caption>NW PATIENT NUMBERS 2006-2022</caption> <thead> <tr> <th>Year</th> <th>Invasive</th> <th>Non-Invasive</th> </tr> </thead> <tbody> <tr> <td>2006</td> <td>27</td> <td>37</td> </tr> <tr> <td>2009</td> <td>49</td> <td>88</td> </tr> <tr> <td>2010</td> <td>56</td> <td>92</td> </tr> <tr> <td>2011</td> <td>55</td> <td>90</td> </tr> <tr> <td>2021</td> <td>61</td> <td>230</td> </tr> <tr> <td>2022</td> <td>61</td> <td>227</td> </tr> </tbody> </table> </div> <p>Patient numbers:</p> <ul style="list-style-type: none"> - Alder Hey overall patient numbers: <ul style="list-style-type: none"> o Non-invasively ventilated – 137 o Invasively ventilated – 27 - Manchester overall patient numbers: <ul style="list-style-type: none"> o Non-invasively ventilated – 90 (?additional 2 to be added) o Invasively ventilated – 34 (?additional 2 to be added) <p>RMCH:</p> <ul style="list-style-type: none"> - Still experiencing delays with recruitment and getting care packages in place - Over 290 training sessions in the 'better at home suite' delivered since January. This and having the carers now recruited to the children is improving the rate of discharges. <p>AHCH:</p> <ul style="list-style-type: none"> - Seeing a significant increase in numbers in this year so far - Waiting for care packages to be set up for 2 IV patients 	Year	Invasive	Non-Invasive	2006	27	37	2009	49	88	2010	56	92	2011	55	90	2021	61	230	2022	61	227	
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<ul style="list-style-type: none"> - One IV patient is on PICU unwell - In addition to the new set ups, also working through the ventilator swap outs for existing patients <p>Helen Campbell noted that it would be useful to break down the numbers by DGH provider. This will help with planning local provision. Elaine stated that she will work on this for the next meeting.</p>	EO
<p>4. Update of workplan, workstreams and working groups</p>  <p>Year 2 priorities 8.3.2023 (Q3) LTV.do</p> <p>LTV Nurses & AHP Group:</p> <ul style="list-style-type: none"> - NW nursing and AHP LTV colleagues come together to discuss consumable needs, issues, updates re field notices etc - Meet every other month virtually - Have incorporated an educational component to the meetings - Holding a face-to-face training day on Monday 26th June at Alder Hey <ul style="list-style-type: none"> o Will be a practical session using simulation o Invite to be shared when details confirmed o Please save the date <p>LTV Education Group:</p> <ul style="list-style-type: none"> - Last met on the 2nd March and next due to meet on the 23rd March - Initially met last year to scope out education and what is required across the region - Reviewed West Midlands Standards - Agreeing set of competencies - Developing exemplars for each of the competencies (to go on ODN website) - Will do gap analysis to see what isn't covered, then we will look as a network to see how this can be addressed - Meetings to take place monthly for the next 6 months <p>Maintenance Group:</p> <ul style="list-style-type: none"> - Different levels of maintenance cover across the North West - In Manchester, the equipment is purchased by Manchester through NHSE monies. The CCGs pay into a maintenance contact with Manchester. So, it is a very smooth process for equipment getting maintained/replaced at Manchester for patients. - At Alder Hey equipment is purchased through NHSE monies and for maintenance there is not robust cover currently as CCG's have to try and find companies to spot purchase contracts from. - Aiming to replicate the Manchester model at Alder Hey - A future expansion of the model at both sites would potentially look to include cough assists 	
<p>5. Level 2 beds – service development planning</p> <p>Each provider has been allocated just under £14k from the PCC service development monies. This was sent to trusts on the 13th January 2023. This is for training to upskill the paediatric workforce. The monies are also to fund roles at the tertiary centre for LTV education and OT. A SIM baby has also been funded to facilitate training, and some acute ventilators are in the process of being signed off, which will be for the level 2 centres. In due course, a process will be rolled out for expressions of interest to be submit for the centres with a desire to become commissioned for level 2, or there will be pilot sites initially. Clarification will be provided as soon as this is possible.</p> <p>Level 2 PCC is HDU level care, so level 2 beds in the region will allow LTV patients to be cared for closer to home, rather than the patients having to come to the tertiary centres, which also causes pressure for the tertiary centres.</p>	

Delayed discharge has been a big issue nationally. At Alder Hey there are 4 TCU beds and at RMCH there are 6 beds which has been stepped up to 7 as a surge. At Alder Hey there is the complex discharge team, which gets the children out in a timely manner. In Manchester some children are getting blocked due to housing and package delays.

As an ODN we have met with the hospices to see if the hospices would be able to accept step down, but the feedback from the hospices is that they are under strain at present and do not have the capacity to offer anything extra. So, the pathways out of the trusts need to be focussed on to make discharges more efficient.

Jonathan noted that delays are often caused by waiting for panels to take place and then for care packages to be recruited to once the go ahead has been agreed. It would be helpful for the pathway to be streamlined. Elaine stated that the ODN are to look at this moving forward.

Jo flagged that it is useful to put incident forms in for delayed discharges and ensure it is on risk registers, as this continues to highlight the issue. The knock-on effect to children who can't access services and cancelled operations is huge on account of LTV children being stuck in PCC beds.

6. Updates – Local teams and linked networks

RMCH:

- Concerns with delayed discharges as already discussed.

AHCH:

- Ok at present
- Have a patient in at present with a safeguarding issue
- Care providers training takes about 8 weeks, takes place within hospital and at home
- Having open conversations with families about the difficulties with getting care packages, and the challenges with having a care package in your home

Zoe's Place:

- Going ok
- Open full time
- Taking vent patients (IV and NIV)
- Have had discussions with AHCH about providing respite, so this is available if required

Claire House:




- Still taking vented patients
- Have just received a new referral for a patient who is coming in a few weeks


Derian House:

- Have a perinatal team, so involved with families right from the birth
- The patient numbers are increasing, now up to 48
- Have 26 beds, but this is a mix of children and adults
- Offer time off the ward to RMCH patients

WellChild:

- New booklet resource launched by WellChild
- Alongside one of our WellChild Nurses - Janice Fauset-Jones, a WellChild Specialist Practitioner (Transition Nurse for Complex Needs and Long-Term Ventilation) based in the Long-Term Ventilation Team at Royal Manchester Children's Hospital we have produced a booklet for young people and young adults (11+) about growing up with a ventilator. The resource covers topics such as:
 - o Ventilator support and care
 - o Health, lifestyle, and leisure
 - o Travel

<ul style="list-style-type: none"> ○ Education and work ○ Managing Emotions ○ Further support and information - The booklet was also written in conjunction with the North West Ventilation Unit at Wythenshawe Hospital, Manchester University NHS Foundation Trust; and with input from young people who use ventilators, MFT Youth Forum, Nurse Specialists, Physiotherapists, and Psychologists from the Children’s and Adult LTV teams at MFT. - The booklet is free and can be downloaded using this link: https://www.wellchild.org.uk/for-professionals/research-resources/growing-up-using-a-ventilator/ - Please share with colleagues 	
<p>7. National update</p> <p>Competencies:</p> <ul style="list-style-type: none"> - As part of the national LTV ODN group we have been looking at education. Elaine has joined the workstream, although the work was well established when joined. The focus is on the competencies and guidelines for the level 2 DGHs. This will be looked at by the NW LTV ODN education workstream and will go on the ODN’s website when ready. The competencies will also be useful for the hospices caring for LTV children. <p>Bivona Field Safety Notice:</p> <ul style="list-style-type: none"> - Notice circulated by NTSP and MRHA: https://tracheostomy.org.uk/news/nhs-england-safety-alert-smiths-bivona-tracheostomy-tubes-1 <div style="text-align: center;">  <p>Bivona Silicone Trache Tube Safety I</p> </div> <ul style="list-style-type: none"> - Please link in with the tertiary centre if you have any children that this applies to <p>Philips:</p> <ul style="list-style-type: none"> - Continuing with repair and replace - Alder Hey further forward than RMCH with this at present 	
<p>8. Risks</p> <p>Presentation given by Helen Blakesley:</p> <div style="text-align: center;">  <p>LTV Risk register.pdf</p> </div>	
<p>9. ODN Website</p> <p>Presentation given by Helen Blakesley:</p> <div style="text-align: center;">  <p>PCC, SiC, LTV, ODN Website LTV Mar 20.</p> </div> <p>https://northwestchildrensodnhub.nhs.uk/</p>	
<p>9. Oversight Group Terms of Reference</p> <p>As an action, community team representation on this group is to be looked at. The Terms of Reference will then be updated and shared for approval.</p>	JM/EO
<p>10. Moving forward - next steps</p> <ul style="list-style-type: none"> - Continuation of equipment and maintenance work 	

- Work ongoing with education group in preparation for the rollout of the level 2 centres	
11. Any other business No items raised.	
12. Education Session - Supporting children into the community Presentation given by Elaine O'Brien:  National LTV Presentation.pptx	
13. Upcoming Meetings: <ul style="list-style-type: none"> • 16th June 2023 13:00-15:00 - Teams • 8th Sept 2023 13:00-15:00 - Teams • 1st Dec 2023 13:00-15:00 - Teams 	

Summary of actions:

- Patient numbers: Helen Campbell noted that it would be useful to break down the numbers by DGH provider. This will help with planning local provision. Elaine stated that she will work on this for the next meeting - **EO**
- Oversight Group Terms of Reference: As an action, community team representation on this group is to be looked at. The Terms of Reference will then be updated and shared for approval – **JM/EO**

Appendix 1 – Attendance & Apologies:

Attendees:

Network

Joanna McBride, Network Director, NW PCC/SIC/LTV ODN's
Elaine O'Brien, Lead Nurse, NW LTV ODN and LTV Nurse Consultant, Alder Hey
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
Andrea Doherty, Service Specialist, NHS NW
Emma Anderton, LTV Discharge Coordinator, RMCH
Helen Campbell, Assistant Director of Nursing, ELHT
Jonathan Haydock-Watson, Complex Discharge Lead, RMCH
Jane Enright, LTV Nurse, Derian House Hospice
Joanne Hill, Practice Education Facilitator, Claire Hill
Meg Ruecroft, Specialist Physiotherapist in LTV, Alder Hey
Michelle Wright, Head of Care, Zoe's Place Baby Hospice
Miles Taylor, Improvement Manager for NHSE Lancs and South Cumbria (inc GiRFT and RightCare)
Natalie Wilkinson, Specialist Physiotherapist in LTV, Alder Hey
Nicola Hunter, Claire House Children's Hospice

Apologies:

Emma Sturt, Jo Douglas, Tracy Drew, Sarah Jackson, Michele Brooks, Clare Halfhide, Stuart Wilkinson, Catherine Davies, Naomi Simmons, Linda Partridge