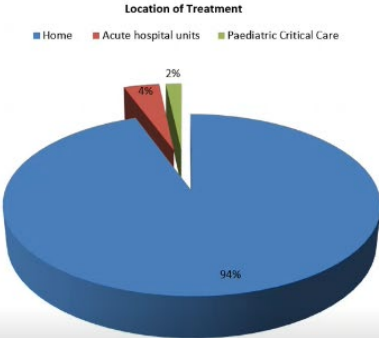


North West ODN Oversight Group for Paediatric Long Term Ventilation

16th September 2022 10:00-12:00 Via MS Teams

MINUTES

	Item	Action																																												
1	<p>Welcome and Introductions</p> <p>Elaine O'Brien welcomed attendees to the meeting.</p> <p>For attendance and apologies, please see appendix 1.</p>																																													
2	<p>Review of patient numbers</p> <p>Presentation given by Stuart Wilkinson and Elaine O'Brien:</p> <div data-bbox="225 952 1321 1467" style="border: 1px solid #ccc; padding: 10px; margin: 10px 0;"> <p style="text-align: center; color: #76923c;">North West LTV Patient Location</p>  <p style="text-align: center; font-size: small;">Location of Treatment</p> <ul style="list-style-type: none"> ■ Home ■ Acute hospital units ■ Paediatric Critical Care </div> <ul style="list-style-type: none"> - Majority of children at home - Still a proportion of children in hospital who are fit for discharge <div data-bbox="225 1574 1321 2101" style="border: 1px solid #ccc; padding: 10px; margin: 10px 0;"> <p style="text-align: center; color: #76923c;">Dec 2021- May 2022- No real change in last 3 months</p> <table border="1" style="width: 100%; border-collapse: collapse; font-size: small;"> <thead> <tr> <th>DECEMBER</th> <th>Manchester</th> <th>Alder Hey</th> <th>NW Total</th> <th>National (2018)</th> <th>NW%</th> </tr> </thead> <tbody> <tr> <td>Invasive (Tracheostomy)</td> <td>27</td> <td>28</td> <td>55</td> <td>445</td> <td>12%</td> </tr> <tr> <td>Non Invasive (Mask)</td> <td>90</td> <td>127</td> <td>217</td> <td>2108</td> <td>10%</td> </tr> <tr> <td>Overall Total</td> <td>117</td> <td>155</td> <td>272</td> <td>2553 /3016**</td> <td>11%</td> </tr> </tbody> </table> <table border="1" style="width: 100%; border-collapse: collapse; font-size: small;"> <thead> <tr> <th>May 2022</th> <th>Manchester</th> <th>Alder Hey</th> <th>NW Total</th> </tr> </thead> <tbody> <tr> <td>Invasive (Tracheostomy)</td> <td>34</td> <td>27</td> <td>55</td> </tr> <tr> <td>Non Invasive (Mask)</td> <td>92</td> <td>138 (+20)</td> <td>217</td> </tr> <tr> <td>Overall Total</td> <td>126</td> <td>165 (185)</td> <td>291 (311)</td> </tr> <tr> <td colspan="4" style="text-align: center; background-color: #fce4d6;">Increase of 19 patients in 6 months</td> </tr> </tbody> </table> </div>	DECEMBER	Manchester	Alder Hey	NW Total	National (2018)	NW%	Invasive (Tracheostomy)	27	28	55	445	12%	Non Invasive (Mask)	90	127	217	2108	10%	Overall Total	117	155	272	2553 /3016**	11%	May 2022	Manchester	Alder Hey	NW Total	Invasive (Tracheostomy)	34	27	55	Non Invasive (Mask)	92	138 (+20)	217	Overall Total	126	165 (185)	291 (311)	Increase of 19 patients in 6 months				
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Patient Flow

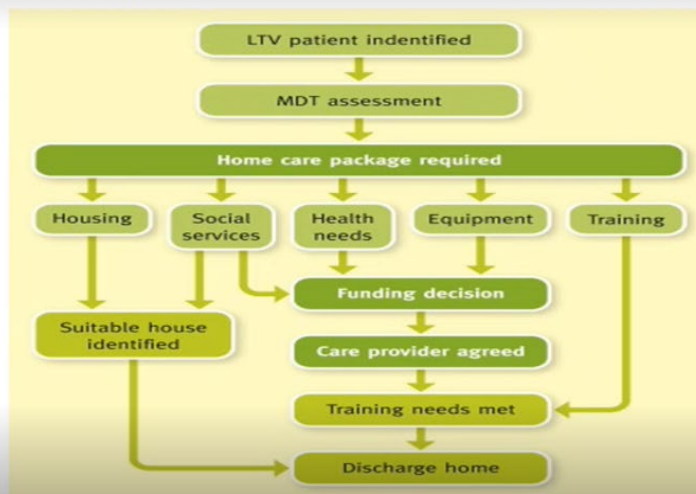
Alder Hey

- ▶ Since last update have increasing amount to PCC LTV delays.
- ▶ Children in TCU awaiting carer recruitment and training

Manchester Children's

- ▶ Extra bed remains on LTV unit +Significant effort placed to discharge+ Quality and highly efficient training average 2-6 weeks
- ▶ Now reduced critical care delays
- ▶ 11 children now in over the 90 day target for home- Crit care and ward
- ▶ Delay factors care package recruitment and housing

Pathway review



- As a team we are looking at the delay between LTV assessment and care package decision/tendering
- There are also delays regarding recruitment of carer teams; there is currently a carer shortage nationally (private agencies, T&Cs, pay, amount of responsibility they have, turnover)
- Housing delays in Manchester
- Training delays at Alder Hey
- Training for carers in Manchester is done in-house, so less delays
- We are looking at getting the pathway running more efficiently and getting the children discharged more timely
- Continuing care assessment – National service framework gives a 6-week timeframe for a package to be allocated – Several areas have significantly breached this
- Sometimes areas may struggle with commissioning when parents have requested personal health budget which may cause a delay
- After discharge, gaps in packages are a huge problem; parents often end up being the contingency plan
- National repository of providers would be useful
- Regional audit could be done to look at what families are commissioned for versus what they actually get – it feels on discharge parents want the package to be 100% set up – rather than set up to fail, would be good to see what parents think
- What is the level that package can be set up for at discharge to be safe? e.g. 70%

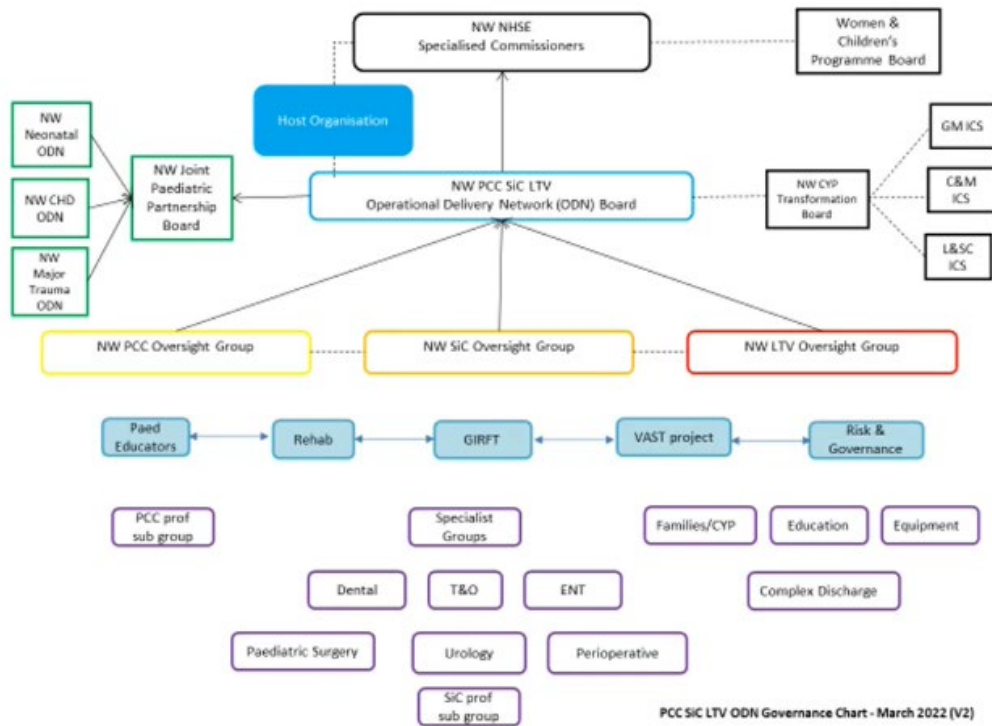
3 Update of workplan, workstreams and working groups

Presentation given by Elaine O'Brien:



ODN Oversight Presentations re wo

Updated ODN Governance Structure:



- This group sits in the red box
- We meet quarterly and feed into the ODN Board
- We are developing working groups for the headings in the purple; equipment, education, and working with families via WellChild
- VAST project up and running
- Moving forward with risk, governance and guidelines group

Workplan update: See within presentation

It was noted that the PPV Involvement has been delayed. These delays are due to ODN workstream delays. The ODN is now at a stage where we hope to move forward with the support of WellChild to ensure the views of the children and families are integral to the ODN's projects and focus. We welcome Amy Mitchell the new Director of Programmes to the Network.

Additional work and updates: See within presentation

EOB


4 Level 2 bed – service development planning


Presentation given by Elaine O'Brien:



ODN Oversight Presentations re wo

	<p>Adam Hebden commented that the list of proposals looks very helpful for both the short and long term; i.e. increasing capacity and training going forward.</p> <p>Adam queried, for families with gaps in their packages / package breakdown, is there any options for intermediate provision e.g. from hospices. Elaine O'Brien commented that hospices are keen to help although they are under pressure too, but we are trying to get as many on board as possible and support them with training. Elaine not aware of any other intermediate provision available in the region at present.</p> <p>Michele Brooks also noted that sometimes parents are reluctant to use hospices because of the connotations of what it means to put their child into a hospice. Michelle has spoken to hospices and parents about the terminology and that it can be for step down.</p> <p>Michele Brooks also explained that increasing amounts of parents ask for personal health budgets, to leave their jobs and become paid carers themselves, especially with the shortage of carers. This works to an extent, but when the child enters school, schools say that it is a conflict of interest for a family member to be with the child in school. Wider discussions are now taking place with the education system regarding allowing family members into school.</p> <p>Linda Partridge noted that issues are arising with family members becoming paid carers, and providing care 24/7, as it is impacting on their health and wellbeing, then packages still breakdown.</p> <p>Respite at home is a model that could be helpful for families, as it means that families don't have to travel, sometimes significant distances, to get some respite. This would be outside of the normal package. This service is often provided by the voluntary sector.</p> <p>Jane Enright commented on the importance of getting social care on board, as they see LTV as a health issue, but providing respite for the families is a social issue. Elaine agreed that ICB engagement may support with this.</p> <p>Phil Rigby suggested that some of these issues could be escalated up to the internal POC meeting within Women's and Children's. These issues are very complex and fit with integrated conversations that are going on to try and find solutions. We need to see what connections there are and what is feasible. Phil will take this back and put it on the agenda for a future meeting,</p>	PR
5	<p>Local updates – including incident updates</p> <p>Alder Hey</p> <ul style="list-style-type: none"> - Delayed discharges from PICU, as only have 4 TCU beds - Hoping to increase number of TCU beds to 6, but need to get staff trained to facilitate this - Ventilator changeovers in the community ongoing - Package breakdowns in community needing support, and may potentially result in admissions <p>RMCH</p> <ul style="list-style-type: none"> - Blockages with discharges, so patients stuck in HDU - Need night cover sorted for packages before patients can be discharged <p>Commissioning</p> <ul style="list-style-type: none"> - Michele Brooks – we need to be influential on a wider strategic level to get changes made that will impact on the ground level. Elaine O'Brien asked that if anyone from this group would like to join the All Age Continuing Care Group to represent our 	All

	<p>children and the struggles that they are having, please contact elaine.o'brien@mft.nhs.uk or louise.king@mft.nhs.uk.</p> <ul style="list-style-type: none"> - Phil Rigby – Main work at present is the women’s and children’s transformation agenda. These conversations are very helpful for this work. <p>GM – Soraya Begum</p> <ul style="list-style-type: none"> - Carers’ recruitment very difficult at present - Some agencies stopping taking additional packages on at present - Now working under the MFT provider framework, transitioning at present - Doing scoping work, covering Tameside, Oldham, Stockport, looking at what work the band 3’s are covering, who’s doing the assessments, package provision etc. Will share this work when finished. <p>C&L – Jane Enright</p> <ul style="list-style-type: none"> - CPOC have no team leader in post at present - 2 band 6’s have also left, so staffing pressures at present - There are 3 nurse packages that they are struggling to recruit to at present - CPOC not winning as many packages at present due to the costs involved <p>Preston – Kevin Turner</p> <ul style="list-style-type: none"> - Making some steps towards training nurses for LTV inpatient management for acute phase - Stuart commented that Preston have LTV adult service - Kevin has met with the adult team who have supported with some of his teenage patients <p>Hospices</p> <ul style="list-style-type: none"> - Elaine meeting with hospices, and we are looking to have a hospice group. Aim to bring the hospices in earlier in the pathway. <p>WellChild</p> <ul style="list-style-type: none"> - Alice – Care package campaign ongoing. Also, the issues that the group are raising, e.g. package breakdown, delayed discharges etc, we are seeing these nationally across the WellChild Nurse Network - Amy – New Chief Exec confirmed. Working alongside other charities to lobby government, re: cost of living crisis / energy bills etc. Are hearing that some parents may look to get their children admitted to hospital on account of home energy bills, so this is not a very positive situation. 	<p>SB</p> <p>EOB</p>
<p>6</p>	<p>Risks</p> <p>Presentation given by Helen Blakesley:</p>  <p>LTV Risk register.pptx</p> <p>If the group have any further risks to add or any mitigations, please forward to helen.blakesley@mft.nhs.uk.</p> <p>Adam commented that the last two items are very similar. Helen will discuss with Elaine if these can be combined, and consider increasing the likelihood.</p>	<p>All</p> <p>HB/EO</p>

7	<p>Oversight Group Terms of Reference</p>  <p>ToR NW LTV Operational Oversight</p> <p>Elaine explained that the Terms of Reference have been updated and are attached. The main changes are that the steering groups have been removed, and that the attendees have been updated.</p> <p>Helen suggested adding an ODN rep to the core group to be quorate.</p> <p>Including ICB and PPV engagement will be looked at.</p> <p>Any comments on the Terms of Reference are to be submitted by the end of October, and then they will be considered a final draft.</p>	EO All
8	<p>Moving forward - next steps</p> <ul style="list-style-type: none"> - Audit of care packages – to see what families are actually getting - Work to look at why carers are leaving - Work with NHSE to get issues discussed today escalated - Work with hospices to look at intermediate care - Cost of living crisis and the impact on LTV families - Work with WellChild to ensure we have parental and family involvement - Finalise Terms of Reference 	
9	<p>Any other business</p> <p>Adam congratulated the LTV ODN for setting out so well the pressures and challenges, as well as putting forward proposals which will definitely make a difference.</p>	
10	<p>Close</p> <p>Next meeting: 9th December 2022 1pm-3pm via MS Teams</p>	

Appendix 1 – Attendance & Apologies:

Attendees:

Network

Stuart Wilkinson, Co Clinical Lead, NW LTV ODN
 Elaine O'Brien, Lead Nurse, NW LTV ODN
 Lucy Allton, Lead Nurse, NW SIC/PCC ODN's
 Helen Blakesley, Network Manager, NW PCC/SIC/LTV ODN's
 Jo Birkmyre, Project Support Officer, NW PCC/SIC/LTV ODN's

Adam Hebden, Associate Director of Strategy and Partnerships, RMCH
 Alice Drury, Charitable Programmes Project Manager, WellChild Charity
 Alison O'Leary, WellChild LTV Nurse Specialist, Alder Hey
 Amy Mitchell, Programmes Director, WellChild
 Anna Hughes, ANP for LTV, RMCH
 Flo Bergquist, Parent Educator Nurse Specialist, Alder Hey

Jane Enright, Complex Needs Nurse and Equipment Lead, Pennine
Jenny Dalzell, Associate Director of Strategy and Planning, Alder Hey
Kevin Turner, Paediatric Consultant, Royal Preston
Linda Partridge – Independent Member – Honorary Professor at Nottingham University
Michele Brooks, Strategic Lead, Midlands Lancs Commissioning Support Unit, also covering Merseyside
Michelle Wright, Head of Care, Zoe's Place Baby Hospice
Phil Rigby, W&Cs Service Specialist, NHSE NW
Soraya Begum, Head of Service - Complex Children's Community Nursing Services, Manchester
Toni McBride, LTV Consultant, RMCH

Apologies:

Louise King
Dr Clare Halfhide