



North West ODN Oversight Group for Paediatric Long Term Ventilation

15th December 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, please see appendix 1.</p>	
<p>2. Minutes of last meeting</p> <p>Previous minutes shared for information and agreed.</p>	
<p>3. Actions from last meeting</p> <ul style="list-style-type: none"> • Linda Partridge will contact Partners in Paediatrics regarding the North West LTV ODN being able to disseminate the standards with a view to agreeing and adopting them. Linda will also flag that individuals are having issues with requesting copies through the Partners in Paediatrics website – On today’s agenda • Pan Regional (London) Competencies - Elaine would welcome any comments from this group on the work, including the competencies, which will be coming out soon – No comments received. 	
<p>4. Review of patient numbers</p> <p>Presentation from Stuart Wilkinson regarding RMCH patient numbers:</p>  <p>Vent info for network - RMCH.pp</p> <ul style="list-style-type: none"> - New OT now in post – welcome to Sinead Phillips <p>Presentation from Elaine O’Brien regarding AHCH patient numbers:</p>  <p>Long Term Ventilation - Patient</p> <ul style="list-style-type: none"> - Patient numbers increasing significantly; lots of new set ups - Trying to deal with this by aiming to put the level 1 patients on the basic ventilators to manage costs, also transitioning patients as appropriate 	

5. Case review – Ventilated patient in DGH

Presentation given by Rebecca Leeming and Clare Swallow:



HE Presentation
LTV.pptx

Discussion/points raised following presentation:

- Elaine O'Brien commented that communication and transferring the patients at the right point is key. Out of hours in the tertiary centres is managed by the respiratory teams as a whole, so it may not always be an LTV specialist on call. The threshold for transfer may need to be lower, until training/education and therefore competence and confidence is increased in the local hospitals. As patient numbers increase this is more and more key.
- The ODN has a work stream looking at LTV education. This work will be rolled out when ready.
- The ODN is also in the process of developing a transfer pathway. This will be shared when ready.
- Gabi Lipshen noted that centres have trouble transferring these patients. In Bolton, they generally aim to keep these patients, but it can feel quite uncomfortable in terms of changing ventilator settings/pressures, having no spare equipment if needed, etc. More support is needed in terms of keeping these patients and also transferring them out when needed. Consistent approach needed for transferring patients out.

6. Update of workplan, risks, workstreams and working groups

Presentation given by Janice Fauset-Jones:



LTV Oversight
151223.pptx

ODN Update:

WCP – transformation programme

- Case for change confirmed
- PCC is one of 4 workstreams
- There will be thorough engagement process beginning Jan 2024
- After 6 month period, need to develop long list of options, short list, and then preferred option
- The public will be consulted on the preferred option

SDF 2023 / 2024 - Monies for PCC level 2




- Training & Education
- Equipment
- L1 / L2 audit (started Dec 2023)

Patient & Public Voice Partners (PPV)

- You are needed to share your opinion / raise your voice!
- Links on the website: <https://northwestchildrensodnhub.nhs.uk/>
- Poster available to print off and display in clinical areas



PPV Poster - 02 11
2023.pdf

<p>7. LTV Survey Results</p> <p>Presentation given by Anna Parry:</p>  <p>LTV Consultant data.pptx</p>	
<p>8. Level 2 beds – service development planning</p> <p>Already covered in the presentation at agenda item 6.</p>	
<p>9. National update</p> <ul style="list-style-type: none"> - RSV spike 3 weeks early – settled now - New RCPCH RTI guidance out https://www.rcpch.ac.uk/resources/guidance-management-children-viral-respiratory-tract-infections - Increased number in electives cancelled – related to PICU capacity - ICB delegation for specialist services – North West 2024 - National PEWS rollout is imminent but delayed currently due to Martha’s rule being brought in - Martha’s rule – process for worries and concerns escalation 	
<p>10. Midlands LTV Quality Standards</p> <p>Presentation given by Janice Fauset-Jones:</p>  <p>MCLTVN Quality Standards.pptx</p> <p>Midlands LTV Quality Standards attached for your review:</p>  <p>MCLTVN QS STANDARDS V5 FIN/</p> <ul style="list-style-type: none"> - Please send any comments to louise.king@mft.nhs.uk by Friday 16th February 2024. - An audit tool is being developed in the West Midlands which will be shared with the ODN when ready, for us to adopt. 	All
<p>11. Updates – Local teams and linked networks – By exception</p> <p>WellChild update:</p> <ul style="list-style-type: none"> - Family Welfare Advice Service just launched - A pilot service providing support for families in the North-West of England applying for disability benefits, grants and more - Family Advisor Service Online Referral Form (one for professionals and one for parents to self-refer): Family Welfare Service WellChild - New platform also launched - interactive platform for finding accessible services, activities and support: In Your Area WellChild - These links will be added to the ODN’s website - Catherine stated that she will contact Janice regarding promoting these opportunities to parents 	LK CD/JFJ

<p>RMCH</p> <ul style="list-style-type: none"> - New Breas circuits have a flip cap on the end, which is a risk for children, as they could open it. This issue has been raised with Breas, but as the majority of them are supplied for adult use, they don't want to make a change as it is not financially viable. Alternative solutions are now being considered. - All children now changed over from Trilogy to Nippy ventilators <p>AHCH</p> <ul style="list-style-type: none"> - In relation to circuits, Elaine explained that Alder Hey don't use the Breas circuits, they build their own circuits. For this, training has to be robust and risk assessments have to be in place. - Long-term stay patient has now been discharged. Gemma's role has been key to this and has received excellent feedback from the community team. More requests are also being received from hospices for support. 	
<p>12. Any other business</p> <p>No items raised.</p>	
<p>13. Next meeting</p> <p>1st March 2024 13:00-15:00 - Teams</p>	

Summary of actions:

- Midlands LTV Quality Standards - Please send any comments to louise.king@mft.nhs.uk by Friday 16th February 2024.
- WellChild new resources:
 - Links will be added to the ODN's website - LK
 - Catherine stated that she will contact Janice regarding promoting these opportunities to parents

Appendix 1 – Attendance & Apologies:

Attendees:

Network

Joanna McBride, Network Director, NW PCC/SIC/LTV ODN's
Stuart Wilkinson, Co-Clinical Lead, NW LTV ODN
Clare Halfhide, Co-Clinical Lead, NW LTV ODN
Janice Fauset-Jones, Lead Nurse, NW LTV ODN
Anna Parry, Nurse Educator, NW PCC/SIC/LTV ODN's
Louise King, ODN Management Support Officer, NW PCC/SIC/LTV ODN's

Amiee Wilde, Bolton

Anna Oddy, Rochdale

Catherine Davies, WellChild Family Engagement Manager

Claire Duncan, Practice Educator for Swanton care and community for complex care children's and young people in Liverpool

Clare Swallow, Ward Manager, Blackpool Teaching Hospital

Dunni Kehn-Alafun, WellChild Project and Engagement Manager, WellChild Nurses and Better at Home Programmes

Elaine O'Brien, LTV Nurse Consultant, Alder Hey

Elizabeth Tahsin, LTV Specialist Nurse, RMCH

Florence Bergquist, Wellchild Parent Educator Nurse Specialist, Alder Hey

Gabi Lipshen, Community Paediatrician, Bolton

Gemma Williams, LTV Educator, Alder Hey

Jane Enright, LTV Nurse, Derian House

Joanne Hill, Claire House

Katie Farrow, Philips

Meg Ruecroft, LTV Physiotherapist, Alder Hey

Michelle Hawkins, Zoe's Place

Natalie Wilkinson, LTV Physiotherapist, Alder Hey

Nic Hunter, Claire House

Phil Rigby, W&Cs Service Specialist, NHSE NW

Rebecca Leeming, Blackpool Teaching Hospital

Sinead Phillips, Occupational Therapist, RMCH

Apologies:

Tracy Drew, Lisa Harvey, Helen Blakesley, Sam Collins, Fran Campion, Tracy Drew, Jo Douglas, Jonathan Haydock-Watson, Linda Partridge