




North West ODN Oversight Group for Paediatric Long Term Ventilation

15th September 2023 14:00-16:00 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. Introduction of New ODN Team Members</p> <p>Jo welcomed to the group the new ODN members:</p> <ul style="list-style-type: none"> • Janice Fauset-Jones - Lead Nurse, NW LTV ODN • Anna Parry - Nurse Educator, PCC, SiC and LTV ODN • Fran Campion - Lead Nurse, Surgery in Children (SiC) ODN • Elaine O’Brien has left her post as Lead Nurse for the LTV ODN, she is stepping in to cover sickness as clinical lead support to the LTV ODN. 	
<p>3. Minutes of last meeting</p> <p>Previous minutes shared for information and agreed.</p>	
<p>4. Review of patient numbers</p> <p>Alder Hey:</p> <ul style="list-style-type: none"> - 169 total LTV patients - 22 invasive patients (on downward trend – only two new set-ups this year so far) - 147 NIV patients (on upward trend – 48 new set-ups this year so far – many more being picked up in sleep studies) - Numbers of NIV patients in Wales has doubled - Please see attached slides for more information: <div style="text-align: center;">  <p>Long Term Ventilation - patient</p> </div> <p>RMCH:</p> <ul style="list-style-type: none"> - To be confirmed following meeting. <p>For the education working group, Linda Partridge commented that it would be useful to have a breakdown of where/which settings all the patients are i.e. in community, hospices etc. Elaine stated that Alder Hey have 5 inpatients, 1 of which is acutely unwell. One patient is on home leave, due to be discharged soon. The rest of the patients are in the community. About 40% of the patients are under hospice care.</p>	

<p>5. Update of workplan, risks, workstreams and working groups / feedback from the Regional Study Day 26th June</p> <p>Presentation given by Jo McBride:</p>  <p>LTV Oversight 150923 Slides.pptx</p> <p>Feedback from the Regional Study Day 26th June:</p>  <p>Feedback from NIV Training Day June 21</p>	
<p>6. Level 2 beds – service development planning</p> <p>Please see Level 2 update included in Jo’s slides at item 5.</p> <p>Update from Phil Rigby – Women’s and Children’s Transformation programme:</p> <ul style="list-style-type: none"> - After passing through gateway 1 a few months ago, the case for change was agreed, and the focus is now moving onto engagement. - A wide programme of engagement is to be delivered, supported by the ODN. - What works well, what needs to improve. - Driven by standards and quality. - Long term plan – 10 years+ - Staff will be engaged with extensively. - A list of options will be developed. - Public and patient surveys will be developed. - Engagement is to include the third sector and other associated organisations as well as the NHS. - Phil encouraged the group to flag up if there are any organisations who are not yet included but should be. - Michele queried if there will be any market management, as the ICBs she works with are struggling re care providers to fill the packages, and also nurses to give clinical oversight. Phil agreed that recruitment and retention is a big issue. There is awareness nationally of this issue. - Jo commented that following the regional study day, there has been interest from a hospice in accessing LTV training, so this is a positive step in expanding services that LTV children can access. 	
<p>7. National update</p> <p>Please see Jo’s slides at item 5.</p>	
<p>8. Midlands LTV Quality Standards</p> <p>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.</p>	LP
<p>9. Updates – Local teams and linked networks</p> <p>Alder Hey:</p> <ul style="list-style-type: none"> - No stable LTV patients on PICU - Several package breakdowns - Having children with acute admissions, and then delayed discharges as families await packages being re-established - Significant issues with maintaining packages for patients in rural areas 	

RMCH:

- Currently doing well with retention of carers, but are having difficulties with recruitment and housing.
- Due to housing issues they have one patient who has a significant delayed discharge. This is being escalated.
- A few patients on PICU
- Chloe commented that for the complex care team in Greater Manchester, working with one provider and honing that relationship is working well. Children are attending hospital less, with less package breakdowns. The patients have their regular staff, but there can be rotation between the teams to cover any gaps. Getting very positive feedback.

Bivona Alert:

- Vigilance encouraged regarding Bivona tubes
- Community colleagues should contact their lead centre for guidance
- Safety alert:



Bivona Silicone
Trache Tube Safety I

WellChild:

- Have a new family support worker programme – currently raising profile –
 - o Natalie Hartgroves, Family Welfare Advisor, is supporting this programme
 - o Lot of housing issues at present which families need support with
 - o Can offer support for families with applying for funding such as PiP, DLA, grants etc
- Have helping hands charitable programme for garden transformations for families. Families can be put forward for this with a supportive letter from their healthcare professional. Applications open up again next week.
- In June, launched the 8 principles for transition (which Janice was involved with in her previous role). Now looking to do the next steps alongside the ready, steady, go programme. If there is anyone from the ODN interested in being involved in the work, please contact Amy.

10. Pan Regional (London) Competencies

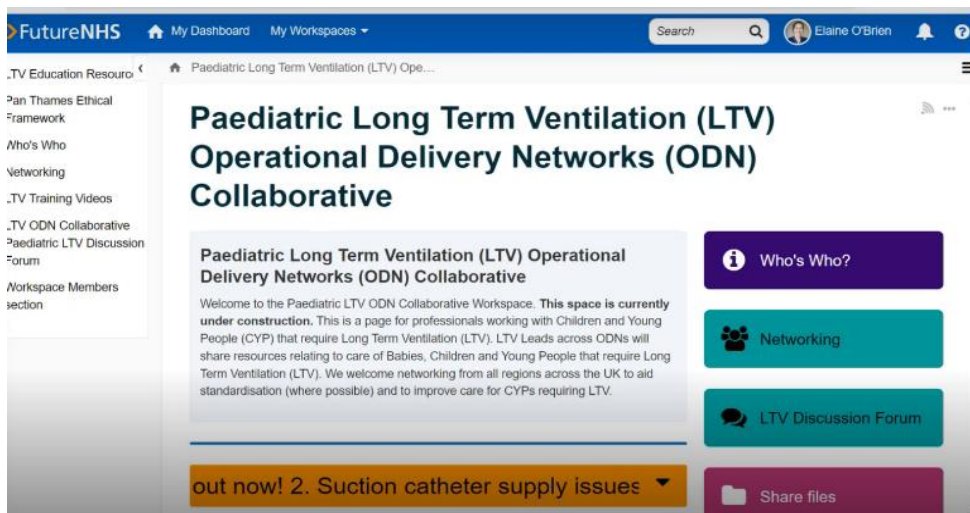
Presentation given by Elaine O'Brien:



ODN Collaborative
Presentaion .pptx

Elaine encouraged the group to join NHS Futures, and access the following page:

<https://future.nhs.uk/cypltvodngroup/grouphome>



Elaine has collaborated on the work, which has been led by the Pan London team. Elaine would welcome any comments from this group on the work, including the competencies, which will be coming out soon.	All
11. Education session: Please see Elaine's presentation above.	
12. Any other business Gemma Williams introduced herself as the new LTV Educator at Alder Hey.	
13. Next meeting 15 th Dec 2023 13:00-15:00 - Teams	

Summary of actions:

- 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.
- Pan Regional (London) Competencies - Elaine would welcome any comments from this group on the work, including the competencies, which will be coming out soon.

Appendix 1 – Attendance & Apologies:

Attendees:

Network

Joanna McBride, Network Director, NW PCC/SIC/LTV ODN's
Janice Fauset-Jones, Lead Nurse, NW LTV ODN
Helen Blakesley, Network Manager, NW PCC/SIC/LTV ODN's
Anna Parry, Nurse Educator, NW PCC/SIC/LTV ODN's
Fran Campion, Lead Nurse, NW SiC ODN
Louise King, ODN Management Support Officer, NW PCC/SIC/LTV ODN's

Amy Mitchell, Director of Programmes, WellChild
Aysha Begum, Children's & Young People's Complex Care Packages, Countess of Chester
Chloe Bulmer, Team Leader, Complex Care Manchester
Dunni Kehn-Alafun, WellChild Project and Engagement Manager, WellChild Nurses and Better at Home Programmes
Elaine O'Brien, LTV Nurse Consultant, Alder Hey
Florence Bergquist, Wellchild Parent Educator Nurse Specialist, Alder Hey
Gemma Williams, LTV Educator, Alder Hey
Helen Beard, Bridgewater Community Healthcare NHS Foundation Trust
Hollie Reynolds, Senior Children's Community Nurse, St Helens and Halton
Jane Enright, LTV Nurse, Derian House
Jane Molyneux, Complex Care Packages, Countess of Chester
Katie Ceraldi, Ward Manager, ELHT
Kim Swan, Senior Nurse, Childrens Continuing Care for Lancashire and South Cumbria
Linda Partridge, Independent Member
Lisa Harvey, Lead Nurse Technology Dependent Children, Betsi Cadwalider University Health Board (North Wales)
Michele Brooks, Head of CYP Service, Midlands and Lancashire Commissioning Support Unit
Michelle Kay, Sister, Trafford Community
Natalie Hartgroves, Family Welfare Advisor, WellChild

Natalie Wilkinson, LTV Physiotherapist, Alder Hey
Nicola Bie, Senior Team Leader, Continuing Care Team Wirral
Paula, McCrindle, Wirral
Phil Rigby, W&Cs Service Specialist, NHSE NW
Sam Collins, Parent Educator for LTV, RMCH
Soraya Begum, Head of Service - Complex Children's Community Nursing Services, Manchester
Zowie Camps, LTV Team, Oldham

Apologies:

Elizabeth Tahsin, Joanne Hill, Meg Ruecroft, Jonathan Haydock-Watson, Naomi Tull, Tracy Drew, Michelle Wright,
Gabi Lipshen, Stuart Wilkinson