


North West ODN Oversight Group for Paediatric Long Term Ventilation

20th September 2024 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>All previous minutes are available on the ODN's website: https://northwestchildrensodnhub.nhs.uk/</p> <p>Dunni Kehn-Alafun will arrange for the ODN's website link to be added to the WellChild website.</p>	<p>DK</p>
<p>3. Actions from last meeting</p> <p>No actions carried forward from last meeting.</p>	
<p>4. Review of patient numbers</p> <p>Presentation from Natalie Wilkinson regarding Alder Hey patient numbers:</p>  <p>Long Term Ventilation - ODN p</p> <p>Comments following presentation:</p> <ul style="list-style-type: none"> - Alder Hey do not have much of a waiting list due to good staffing levels within the team. - Can now do polysomnographies (sleep studies) at home, so patients are picked up quicker. - Have Down Syndrome screening, which picks up patients from 1 year old. - Seeing increase in Obesity Hyperventilation Syndrome. - NIV technology is improving all the time. So, patients that might have gone into tracheostomies now can be managed on NIV. - Generally, patients are kept out in the community well. <p>Update from Liz Tahsin regarding RMCH patient numbers:</p> <ul style="list-style-type: none"> - NIV patient numbers going up, currently 147, plus 30 on waiting list for sleep bed who will potentially go onto NIV. 	

- 37 IV patients currently.
- Have 5 inpatients, including one that is medically fit for discharge (awaiting housing).
- No patients on PICU at present.
- Flow is much improved. A big contributor to this is the OT who supports greatly with housing.

5. ODN update, Study Days, feedback, workplan, working groups, SDF

Presentation given by Jo McBride and Janice Fauset-Jones:



LTV oversight
meeting 20.09.24.pp

6. National Update

- National PEWS – soft launch
 - Any issues to be reported to England.pews@nhs.net
- Winter prediction – ‘normal’
- RSV vaccination: 1 September 2024
 - RSV: Same vaccination for adults & CYP
 - Palivizumab (for high risk CYP)
 - Focus women 28 week and for newborn babies (Pfizer)
- UKHSA – other infections Pertussis / Measles / Flu / M-Pox
 - Pertussis vaccination – pregnant women 1 July
 - Measles – less but still around
 - Flu vaccination for CYP
 - M-Pox – confirmed case: local plan for an imported case (HCID Tool kit) – history, isolate, PPE, staff log, who have contact, call ID (imported fever service) – specialist team to move CYP if needed to cohort.
- Martha’s Rule
 - This ODN not successful pilot for sharing and learning (Y&H, West Midlands and North Thames to be ODN pilots)
 - Paed pilots: 2 x RMCH / AHCH
 - Adults & paed pilots: Walton, Preston, Bolton
 - This year is a learning year. Working closely with the Patient Safety Collaborative. 143 in total in the first year.
- National LTV Network Meeting - 6th December 2024
<https://forms.microsoft.com/pages/responsepage.aspx?id=uVuEaxKDNUiePezxif4R6fYmQtv0UNIFhB6650I8zxdUODA3OFRNRjQyWIBLWVdYWTIKQIVDSldDTi4u&route=shorturl>


7. LTV Self-assessment

Presentation given by Janice Fauset-Jones:



LTV
Self-Assessments .pjl

Alder Hey volunteered to be the pilot site for the first LTV self-assessment in this region.

<p>Janice also noted that she will speak to local hospital colleagues about a local hospital pilot site. Following the pilots, any updates required will be made to the process, before rolling it out to the region.</p>	<p>JFJ</p>
<p>8. Updates – Local teams and linked networks – By exception</p> <p>Alder Hey - Update from Alison O’Leary:</p> <ul style="list-style-type: none"> - Rolling out training across the wards. - Supporting more patients going through theatre for surgical day cases, to prevent admissions to HDU. - Collating data for how many patients have gone through day case surgery and what procedures they’ve had; NIV and IV. - Training up anaesthetic ANPs and rolling out training across theatres. - Have prevented a lot of admissions of LTV patients, as specialist nurse going to recovery after the patient has had day case surgery, rather than patient having to go to HDU. - Anaesthetist has done audit covering the last couple of years on bed days saved and patient/parent experience. - The saved bed days results in a significant cost saving. - Looking at what other areas are doing for if other areas can benefit from putting this in place. - Group were keen for this service improvement to be shared at the next meeting. It could also be shared at the ODN conference as a poster or case presentation. - Jo will be in touch with Ali to discuss this further. - The model has been shared with RMCH. RMCH are currently looking into if it will be feasible to roll the model out. <p>NHSE - Update from Nikki Childs:</p> <div style="text-align: center;">  <p>LTV Oversight September 2024 WC</p> </div> <p>WellChild - Update from Danni Kehn-Alafun:</p> <ul style="list-style-type: none"> - Danni highlighted that Alison O’Leary’s reports contributed hugely to the £6.1 million savings WellChild posts contributed to the NHS UK-wide for prevented admissions and bed days. - Danni also highlighted the WellChild Family Welfare Advisor Service which helps families caring for a child with complex medical needs to thrive at home by offering support with applying for disability benefits, accessing grants, and providing information on local services. The contact is Natalie Hargreaves, Family Support Advisor. - The service is open to parents/carers in the North West of England and referrals can be made by professionals working with parents, or parents can refer themselves. - In the last 12 months, the service has opened up access to over £600,000 for families in the North West. - https://www.wellchild.org.uk/get-support/family-welfare-service/ - This link is also shared on the ODN’s website. - Please contact dannikehn-alafun@wellchild.org.uk to be put in touch directly with Natalie. 	<p>JMc/ AO</p>

<p>9. Any other business</p> <p>No items raised.</p>	
<p>10. Next meeting</p> <p>13th December 2024 13:00-15:00 - Teams</p>	

Summary of Actions:

<ul style="list-style-type: none"> • Danni Kehn-Alafun will arrange for the ODN’s website link to be added to the WellChild website. 	<p>DK</p>
<ul style="list-style-type: none"> • LTV self-assessment - Alder Hey volunteered to be the pilot site for the first LTV self-assessment in this region. Janice will speak to local hospital colleagues about a local hospital pilot site. 	<p>JFJ</p>
<ul style="list-style-type: none"> • Supporting LTV patients going through theatre for surgical day cases, to prevent admissions to HDU - Group were keen for this service improvement to be shared at the next meeting. It could also be shared at the ODN conference as a poster or case presentation - Jo will be in touch with Ali to discuss this further. 	<p>JMc/ AO</p>

Appendix 1 – Attendance & Apologies:

Attendees:

Network

- Joanna McBride, Network Director, NW PCC SiC LTV ODN
- Janice Fauset-Jones, Lead Nurse, NW LTV ODN
- Helen Blakesley, Network Manager, NW PCC/SiC/LTV & MT ODNs
- Louise King, ODN Management Support Officer, NW PCC SiC LTV ODN
- Anna Parry, Nurse Educator, NW PCC SiC LTV ODN
- Catherine McGee, ODN Educator, NW PCC SiC LTV ODN
- Jessica Budden, ODN Educator, NW PCC SiC LTV ODN
- Kimberley Beer, ODN Educator, NW PCC SiC LTV ODN

- Alison O'Leary, WellChild LTV Nurse Specialist, Alder Hey
- Antonia McBride, RMCH
- Cassandra Barrett, Wirral
- Danni Kehn-Alafun, Wellchild
- Elizabeth Tahsin, LTV Specialist Nurse, RMCH
- Emily Barnes, Community Nurse, Trafford Community Nursing Team
- Florence Bergquist, Wellchild Parent Educator Nurse Specialist, Alder Hey
- Hannah Board, Trafford CCNT
- Jane Enright, LTV Nurse, Derian House
- Jane Molyneux, Chester
- Jenny Dodds
- Mark McNulty, Alder Hey
- Natalie McIlroy

Natalie Wilkinson, Alder Hey

Nikki Childs, Service Specialist for NW Women & Children's Team, NHSE

Ruksana Afsar, LSCFT

Toni Berry-Brown, LSCFT

Apologies:

Cathryn Livingstone, Lisa Wilby, Sara Gornall, Tracy Drew, Clare Halfhide, Elaine O'Brien, Stuart Wilkinson