




North West ODN Oversight Group for Paediatric Long Term Ventilation

16th June 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>Jo informed the group that this will be Elaine O’Brien’s last meeting in her role as Lead Nurse for the ODN. Jo thanked Elaine for all the support she has given to the ODN. Elaine will remain in her role as Consultant Nurse at Alder Hey, so will still input into the ODN from that perspective. The Lead Nurse role has now been recruited to, and the new member of the ODN will commence in post later this summer.</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>Patient numbers:</p> <ul style="list-style-type: none"> - Alder Hey overall patient numbers: <ul style="list-style-type: none">  Long Term Ventilation - patient <ul style="list-style-type: none"> o Large increase in new set ups over the last 6 months – 27 patients (2 of which IV) - Manchester overall patient numbers: <ul style="list-style-type: none">  LTV patient data for the ODN (RMCH).pp <ul style="list-style-type: none"> o NIV set ups have been escalated. Team has expanded to allow this, but still a large waiting list due to bed availability for patients to come in o Also, significant rise in IV o Significant push to get patients out of PCC; 7 patients discharged in last 6 months 	
<p>4. Update of workplan, risks, workstreams and working groups</p> <p>Presentation given by Jo McBride:</p> <ul style="list-style-type: none">  LTV Oversight meeting 16.06.23.pp 	

ODN website link:

- <https://northwestchildrensodnhub.nhs.uk/>

Maintenance Group:

- A lot of background work has been going on, regarding what is possible and costings, and this is now almost ready to share with commissioners

LTV Education Group:

- The working group have a Teams channel where competencies are being collated
- The group are looking at examples of good practice, and who will need what training

Standards:

- West Midlands Standards available on request from Partners in Paediatrics Website: [Midlands Children's Long Term Ventilation Network \(MCLTVN\) - Partners in Paediatrics](#)
- Looking to agree and adopt them in this region

5. Level 2 beds – service development planning

Please see Jo McBride's presentation.

6. Updates – Local teams and linked networks

ODN:

- NIV training day taking place on the 26th June at Alder Hey. Will be a very practical day, and include simulation using the new dolls. The event is now fully booked. Intend to hold more courses in future.
- Suction catheter shortage



Suction-Catheters-
Community-Partners

- Shortage of paediatric NIV masks due to licencing changes (Wisp). The parts to make up a mask are also out of stock. Alternatives having to be used in the interim.
- Field safety notice circulated for the EVO's, in relation to the particulate filters now being mandatory



FSN - Trilogy EVO
filters May 2023.pdf

- Bivona trachy tube issues starting to resolve

AHCH:

- All children now moved over to the EVO ventilators
- Phillips will end their support to the Trilogy 100's next year
- Only one invasive patient in at present
- Ok at present regarding beds
- LTV Educator starting in July
- Parent education leaflet being developed for NIV patients, in collaboration with Manchester. Has been sent out to parents for feedback. Will share when complete.

RMCH:

- No dry circuits at present, no time frame at present for delivery
- Breas rep attending NIV training day and will bring some different circuits to try
- Patients still on the Trilogy 100's awaiting being swapped over. Awaiting delivery of more Nippy's.
- Intermittent catheter supply issues

- Cubicle for sleep bay keeps on being utilised by the Trust for PED. This is an issue, as the cubicle is needed for new NIV set ups. Looking into solutions for this at present.
- OT role out to advert

North Wales:

- Experiencing difficulties with the suction catheters. Can't get hold of the tender tips at present, which one patient requires.
- Prolonged stay for a patient in Alder Hey, due to a package breakdown
- Able to now get trachys
- No respite available for patients at present in North Wales. Ty Gobaith are scoping being able to provide this in future.

NHS Midlands and Lancashire Commissioning Support Unit (MLCSU):

- There have been some delayed discharges/assessments from RMCH perspective, although now all done
- Capacity issues for the services who carry out the health needs assessments for the ICB
- The CSU offered training for carrying out the health needs assessments, which RMCH took up. The CSU is also happy to offer the training to Alder Hey if required (contact leanne.davies19@nhs.net).
- Difficulties with recruitment and retention of staff for care packages having a big impact. This is a national issue. This has led to the breakdown of several packages.

NHS England:

- Have now passed through Gateway 1 for the Case for Change (covers neonatal, PCC, surgery in children services and CYP cancer services)
- Now beginning the engagement process
- Looking at what works well, what needs changing, and what changes are feasible
- Looking at estates, flows, workforce
- This next phase may stretch to March 2024, and by then the aim is that there will be a list of options to consider
- Phil will follow up on where the development of the LTV service specification is up to in priority list

PR

Countess of Chester:

- As a care package team currently only have 1 NIV patient
- No issues at present

Morecambe Bay community care team:

- Having circuit issues but the Manchester team have been supportive to resolve it in the short term
- Same suction catheter issues as others are finding
- Otherwise, all ok

Wirral continuing care team:


- Same issue with suction catheters, although procurement team has set up a standing order to deliver a small number each day and this seems to be working so far

Heywood, Middleton and Rochdale community care team:

- Have 3 IV patients, and several NIV patients
- Same issue with suction catheters
- Have one child that may have to be admitted if care package fails
- Issues with recruitment and retention of carers

Trafford community nursing team:

- No current issues
- Have been well supported by ward 83 and specialist nurses

<p>Greater Manchester complex care team:</p> <ul style="list-style-type: none"> - Issues with suction catheters and wet circuits - Suction catheter issue starting to ease, but still waiting on wet circuits. Being supported by Ward 83, RMCH. <p>Zoe's Place:</p> <ul style="list-style-type: none"> - No issues at present <p>Derian House:</p> <ul style="list-style-type: none"> - No issues at present <p>Ty Gobaith:</p> <ul style="list-style-type: none"> - No issues at present 	
<p>7. National update</p> <p>GIRFT (Getting it right first time):</p> <ul style="list-style-type: none"> - Report published for paediatric critical care which included a lot of focus on LTV - Many PCC bed days are due to LTV patients - Elaine attended recent GIRFT national meeting - Meeting looked at pathway. At what point patients should be stepped up to tertiary care and then stepped back down. Safety and governance for this. - Focus groups to be held, which our region will be included in <p>ODN LTV Education Group:</p> <ul style="list-style-type: none"> - National group being developed to look at education - Most of the ODN's now recruiting educators 	
<p>8. Risks</p> <p>Please see Jo McBride's presentation.</p>	
<p>9. Oversight Group Terms of Reference</p> <p> ToR NW LTV Operational Oversight</p> <p>The group reviewed these in the meeting. The governance structure is to be amended to the updated version, and then the Terms of Reference can be considered signed off.</p>	JM
<p>10. Moving forward - next steps</p> <ul style="list-style-type: none"> - To follow on from the NIV education event taking place this month, it is planned that a future event will be held focussing on invasive ventilation. 	
<p>11. Any other business</p> <p>Day/time for future meetings</p> <ul style="list-style-type: none"> - The group present agreed that they were happy with the meetings as they are, i.e. quarterly on Friday afternoons - However, to capture the views of those not present, it was agreed that a survey will be circulated to gather opinions <p>National ODN Competencies and Guidelines:</p> <ul style="list-style-type: none"> - Elaine will share for comments 	LK EO

- To be discussed in detail at next meeting	
12. Upcoming Meetings:	
<ul style="list-style-type: none"> • 8th Sept 2023 13:00-15:00 - Teams • 1st Dec 2023 13:00-15:00 - Teams 	

Summary of actions:

- Follow up on where the development of the LTV service specification is up to in priority list - PR
- Terms of Reference - The governance structure is to be amended to the updated version, and then the Terms of Reference can be considered signed off – JM (DONE)
- Day/time for future meetings – To capture the views of those not present, it was agreed that a survey will be circulated to gather opinions – LK
- National ODN Competencies and Guidelines - Elaine will share for comments. To be discussed in detail at next meeting – EO

Appendix 1 – Attendance & Apologies:

Attendees:

Network

Joanna McBride, Network Director, NW PCC/SIC/LTV ODN's

Stuart Wilkinson, Co-Clinical Lead, NW LTV ODN

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

Anna Oddy, Complex and Palliative Specialist Nurse, Heywood, Middleton and Rochdale Community Team

Aysha Begum, Children's & Young People's Complex Care Packages, Countess of Chester

Chloe Bulmer, Team Leader Complex Care Manchester

Elizabeth Tahsin, LTV Specialist Nurse, RMCH

Emily Barnes, Manchester Children's Community Nursing Team

Emma Anderton, LTV Discharge Coordinator, RMCH

Florence Bergquist, Wellchild Parent Educator Nurse Specialist, Alder Hey

Helen Templeton, Senior Team Leader, Continuing Care Team Wirral

Jane Molyneux, Complex Care Packages, Countess of Chester

Jenny Dodds, Clinical lead, Children's Community Nursing Team, Lancaster and Morecambe

Joanna Mark, Paediatric Respiratory Nurse Specialist, Oldham CCNT

Josie Hauxwell, Physio Assistant, Derian House

Lauren Sampson, NIV Specialist Nurse, RMCH

Leanne Davies, CYP Clinical Lead at Scale, MLCSU

Lisa Harvey, Lead Nurse Technology Dependent Children, Betsi Cadwalider University Health Board (North Wales)

Michelle Wright, Head of Care, Zoe's Place Baby Hospice

Nicola Bie, Senior Team Leader, Continuing Care Team Wirral

Miles Taylor, Improvement Manager for NHSE Lancs and South Cumbria (inc GiRFT and RightCare)

Naomi Tull, Clinical Practice Educator, Ty Gobaith Children's Hospice

Natalie Wilkinson, Specialist Physiotherapist in LTV, Alder Hey

Phil Rigby, W&Cs Service Specialist, NHSE NW

Rachel Rodgers, MFT

Sally Owen, Childrens and Young Person's Complex Care Packages, Countess of Chester

Sophie Graves, Nurse, NWTS

Tracy Drew, Parent Educator for LTV, RMCH

Vicky Taylor, Senior Nurse CCNT Halton and St Helens

Apologies:

Gabi Lipshen, Jane Enright, Chris Grime, Adam Hebden, Jonathan Haydock-Watson, Katie Farrow, Catherine Davies, Linda Partridge