



North West ODN Oversight Group for Paediatric Long Term Ventilation

1st March 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>3. Actions from last meeting</p> <ul style="list-style-type: none"> • Midlands LTV Quality Standards - Please send any comments to louise.king@mft.nhs.uk by 16th February - No additional comments received • WellChild new resources: <ul style="list-style-type: none"> ○ Links will be added to the ODN's website - Complete ○ Catherine stated that she will contact Janice regarding promoting these opportunities to parents – Complete 	
<p>4. CYP Conflict Management Champions</p> <p>Item deferred to next meeting.</p> <p>Link to Conflict Management webpage: https://www.e-lfh.org.uk/programmes/recognising-%20and-managing-conflict-between-childrens-families-%20and-healthcare-providers/</p>	
<p>5. Review of patient numbers</p> <p>Presentation from Stuart Wilkinson regarding RMCH patient numbers:</p>  <p>Oversight LTV meeting - Stuart Wil</p> <p>Presentation from Elaine O'Brien regarding Alder Hey patient numbers:</p>  <p>Long Term Ventilation - Patient</p>	

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

Presentation given by Janice Fauset-Jones:



LTV oversight meeting 01.03.24.pp

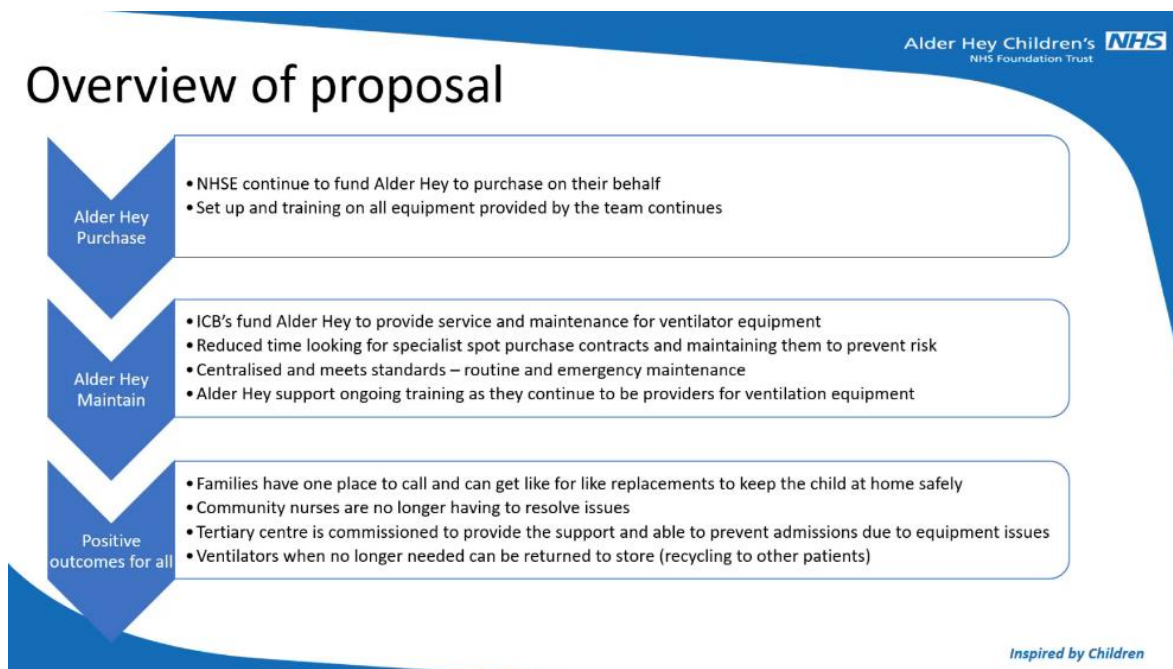
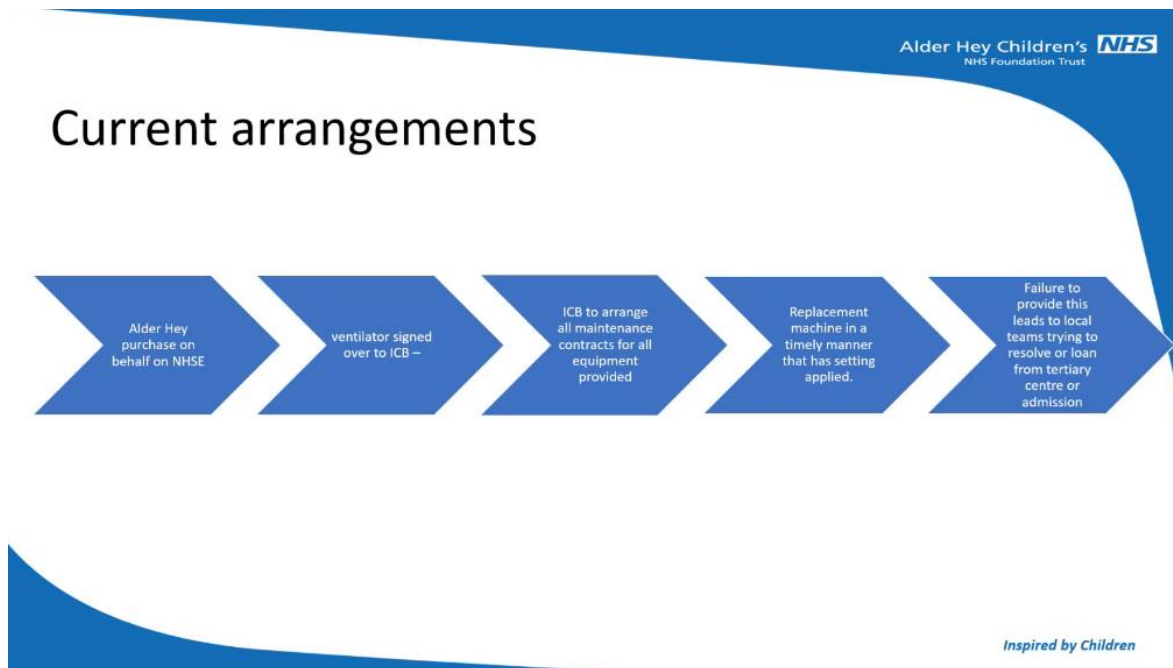


Flyer - LTV Study Days 2024.docx

7. Update on Equipment and Maintenance Work at Alder Hey

Presentation given by Elaine O'Brien:

- Maintenance support for children on LTV
- Centralising maintenance to make it safer, meet standards and improve efficiency



IMPACT

- +Standard approach across the region- Clear pathways that are equitable and not dependent on postcode.
- +Efficient utilisation of equipment
- +Reduced responsibility and pressures on families and community teams
- +Timely access to life support/sustaining equipment, greatly improving safety.

+/- possibly a difference in cost for the enhanced service. This will depend on what contracts are currently held.

Inspired by Children

Comments:

- Concerns that community teams not aware that they are responsible for ventilators once patients out in the community.
- Are there plans that this could eventually be a regional service? At present this would be difficult as Manchester and Alder Hey use different ventilators. Also, data protection would be an issue as patient prescriptions would need to be shared. A regional service could be an aim for the future.

8. Service Development Money

Update given by Jo McBride re: Women's and Children's Transformation Programme:

- Have recently commenced engagement phase.
- Face-to-face event held 13th February and virtual event held 29th February.
- Both events had similar format. Went through case for change, data work around modelling, assumptions of how services currently work. Then attendees were split up into their areas of interest; cancer, PCC, neonatal, and surgery in children. Although there is not an LTV stream, LTV strongly links in with PCC.
- Report from both sessions will be shared when ready.
- The programme includes fixed points, meaning that the tertiary centres will not be moved, and there will be considerations to geography.
- Engagement with service users is also going to be key to the process.
- Will go into design phase after engagement. Will look at what the critical success factors look like.
- It is a large programme with a 10 year expectancy.
- If there is anyone who is interested in getting involved in this work, please contact Joanna.mcbride@mft.nhs.uk.
- Updates on the work will be shared with this group.

9. National update

Update given by Janice Fauset-Jones:

- Infections - Measles /flu / RSV
 - o flu / RSV stable

- Link to RCPCH webinar on Measles: [*NEW* RCPCH Webinar: Measles – an update \(28/02/2024\) – RCPCH Learning](#)
- RSV vaccine - aiming for June 2024 - awaiting confirmation of delivery programme
- Martha's rule / law - 3 key points: <https://www.england.nhs.uk/long-read/implementation-of-first-phase-of-marthas-rule/>
 1. All staff in NHS trusts must have 24/7 access to a rapid review from a critical care outreach team, which they can contact should they have concerns about a patient.
 2. All patients, their families, carers and advocates must also have access to the same 24/7 rapid review from a critical care outreach team, which they can contact via mechanisms advertised around the hospital and more widely if they are worried about the patient's condition.
 3. The NHS must implement a structured approach to obtain information relating to a patient's condition directly from patients and their families at least daily. In the first instance, this will cover all inpatients in acute and specialist trusts. EoI pilot providers (100 sites)
- Digital child record – new system
 - proxy access (for parents / carers for CYP records) – in development
- Service Specifications:
 - Transport – many comments – being reviewed (65 responses received)
 - Level 2 – new lead
- Working groups
 - GIRFT benchmark/ workforce / LTV / DoS / clinical pathways / transport / L1 & L2 education

National LTV Meeting Feedback:

- Please see slides at item 6.

10. Updates – Local teams and linked networks – By exception

Countess of Chester:

- Fairly quiet
- NIV patients doing well, no concerns

Wirral continuing care:


- Quiet, no concerns

Burnley:

- Physiotherapy colleagues have been very supportive with a number of trachy patients who have been struggling with viral illnesses predominantly. Have had a few attendances and admissions.
- Team support families out in the community to try and keep patients at home.

Training:

- Arrowse Park – Alder Hey colleagues planning to give training to support with keeping patients locally. Grand round planned for 6th June.
- Barrow – Alder Hey will be providing ventilation training
- Hospices – Flo Bergquist and Gemma Williams have recently been to Brian House to provide training. Have training coming up with Zoe's Place and Claire House.

<p>11. Any other business</p> <p>Patient and public voice:</p> <ul style="list-style-type: none"> - The ODN would be very grateful if this PPV poster could be printed off and displayed in patient areas. The Womens and Childrens Programme are keen to get engagement from service users through the ODN.  <p>PPV Poster - 02 11 2023.pdf</p> <p>Staffing crisis:</p> <ul style="list-style-type: none"> - There is a risk that some hospice respite stays may need to be cancelled in future due to lack of staff. - There are struggles with recruitment and retention of staff for care packages. This is a National issue. - Package staff in some areas are banded as a 3 and in other areas as a 4. In Chester staff are on a band 4 and retention is generally much better. - Exit interviews as to why staff are leaving can be very helpful. - The nights can be very hard for care staff due to loneliness etc. - Some of the private agencies are offering cash incentives, and are also including a picture of the child (with parent's permission) in adverts. 	
<p>12. Next meeting</p> <p>7th June 2024 13:00-15:00 - Teams</p>	

Appendix 1 – Attendance & Apologies:

Attendees:

Network

Joanna McBride, Network Director, NW PCC/SIC/LTV ODN's
 Stuart Wilkinson, Co-Clinical Lead, NW LTV ODN
 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
 Louise King, ODN Management Support Officer, NW PCC/SIC/LTV ODN's

Alison O'Leary, WellChild LTV Nurse Specialist, Alder Hey
 Amiee Wilde, Bolton
 Anna Oddy, Complex and Palliative Specialist Nurse, Heywood, Middleton and Rochdale Community Team
 Anna Sibley, Consultant Paediatrician, ELHT
 Catherine Davies, WellChild Family Engagement Manager
 Elaine O'Brien, LTV Nurse Consultant, Alder Hey
 Elizabeth Tahsin, LTV Specialist Nurse, RMCH
 Emma Anderton, LTV Discharge Coordinator, RMCH
 Florence Bergquist, Wellchild Parent Educator Nurse Specialist, Alder Hey
 Gemma Williams, LTV Educator, Alder Hey
 Helen Beard, Bridgewater Community Healthcare NHS Foundation Trust
 Helen Templeton, Senior Team Leader, Continuing Care Team Wirral
 Jane Enright, LTV Nurse, Derian House
 Katie Farrow, Philips

Lauren Walker

Leanne Davies, CYP Clinical Lead at Scale, MLCSU

Lisa Flannery, Alder Hey

Meg Ruecroft, LTV Physiotherapist, Alder Hey

Paul Maines, Philips

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

Sinead Phillips, Occupational Therapist, RMCH

Apologies:

Gabi Lipshen, Tracy Drew, Clare Halfhide, Phil Rigby