



North West  
Paediatric Long Term Ventilation  
ODN  
Oversight Group  
Wednesday 23rd February 2022 2pm-4pm Via MS Teams

Agenda Item	
<p><b>1. Welcome and Introductions</b></p> <p>Jo McBride, Network Director, NW LTV ODN, welcomed all to the first North West LTV Oversight Group meeting.</p> <p>The ODN Team were introduced to the group:</p> <p>Jo McBride, Network Director for SIC/PCC/LTV, Elaine O'Brien, Lead Nurse, LTV ODN Jo Birkmyre Project Support Officer.</p> <p>For attendance and apologies, please see <b>appendix 1</b>.</p>	JM
<p><b>2. The Operation Delivery Network - Presentation</b></p> <p> LTV Oversight Launch .pptx</p> <p>Jo McBride gave an overview of the purpose and structure of the North West LTV Operational Delivery Network.</p> <p>Jo also informed the group that the Terms of Reference for the group would be shared with the minutes for review and comments. Currently there are no family/parents attending the meeting, however this is planned and is progressing.</p>	JM
<p><b>3. Work Plan</b></p> <p> Key Priorities for LTV year 1.docx</p> <p>Elaine O'Brien gave an overview of the key priorities for the ODN's first year, informing the group of progress so far.</p> <p><b>Equipment Consumables and Maintenance</b></p> <p>A discussion followed the presentation regarding the issue of maintenance and consumables for equipment, it was decided that a working group would be formed to clarify locations where there are issues and to share information across the region. Jo McBride confirmed that she will raise this issue with Specialised Commissioning. Transition of patients to adult services was also discussed and will be added as an agenda item for the next NW LTV Oversight meeting.</p> <p><b>Standards Update</b></p> <p>Elaine O'Brien informed the group that the West Midlands ODN are currently reviewing their standards and once complete (forecast completion June 2022), the standards should with the North West and then work to see if these can be taken up nationally. There is the possibility of creating a regional standards framework for the North West region, if needed. The West Midland ODN will be represented at the next North West LTV Oversight meeting. There is also opportunity to attend the West</p>	EO

Midland LTV ODN meeting, Elaine asked that anyone interested in attending should contact her directly, at [Elaine.O'Brien@mft.nhs.uk](mailto:Elaine.O'Brien@mft.nhs.uk).

### **WellChild**

Alice Drury gave an update from WellChild, informing the group that there were 8 WellChild posts in the North West region, so the area was well represented. Alice also informed that group that WellChild was a national charity and therefore extremely well linked with other networks and groups and would be able to share to the ODN any learning from work completed with other groups if this was helpful. WellChild have an established families support team and Network and will be happy to support child and family input where possible.

### **National Tracheostomy Safety Project**

Elaine updated on the production issues surrounding supply of paediatric tubes, informing the group that the issue with Bivona tubes has been documented on the NHS Supplychain website, the ODN will share information via email with the network as this is updated. Dr Andrew Bentley updated that adult services had not been affected by the shortage.

### **Paediatric Critical Care ODN**

Elaine O'Brien informed the group that PICU bed state has been critical for some time now, although this is starting to ease. Jo McBride highlighted that PICU beds nationally do not seem as pressured; at the national update last week it was reported that there was capacity across the country. Elaine also added that members of other networks such as the Palatine Care Network would be invited to attend the LTV ODN Oversight meeting. (Thank you for attending today)

## **4. Updates from areas**

### **Tertiary Centres**

Alder Hey have been running at around a 75% capacity, with 1 or 2 patients in at a time in appropriately in HDU/PICU. RMCH have been extremely busy recently, with around 14 patients in at a time, with only 6 LTV beds. There has been a significant number of new referrals which has impacted RMCH heavily. Elaine O'Brien informed the group that a patient is categorised as a delayed discharge after 90 days of stable needs, RMCH currently have 4 delayed discharges, which are due to care package issues.

### **Commissioning**


Emma Sturt highlighted the national shortage of care staff and the difficulties in recruiting which is causing long delays in discharges. There is a huge shortage of high level care across the board, not just in North West region. Passports for carers were discussed, which all agreed would be beneficial. Andrew Bentley added that the shortage of care staff was also an issue in adult care, causing a frequent breakdown in packages. Alice Drury agreed, adding that the WellChild Charity were seeing this nationally, and commented on the impact on families who were struggling to cope. Helen Coutts highlighted the importance of providing support to families who are affected by the breakdown of care packages.

Michelle Brooks informed the group that hospice provision is being used via spot purchase arrangements. This can be a short break provision to alleviate the pressure on families to provide care.

### **NHS Care Provider linked with Community Nursing**

Clare Palmer undated that supply issues have been a challenge. Housing always causes delays in getting children home.

### **DGH's**

<p>Jo Douglas, BCUHB, reported that the number of people applying for care roles is low and retaining staff is a challenge. Staff are finding it incredibly difficult, working in homes highlighting the need to support staff. Jo suggested movement between packages for carers could give carers some relief. There is a large gap in respite care for families. Elaine O'Brien also highlighted the lack of career progression for trained carers, which is causing carers to leave the profession.</p> <p>Cathryn Livingstone from the Complex Discharge Team at Alder Hey commented that the pressure on packages is huge, with no contingencies. Alder Hey don't have the same blockages as other areas, however it is the care package which cause delays in discharge.</p>	
<p><b>5. Excellence in Care Presentation</b>  <b>Complex Care Team, presentation by Cathryn Livingston, Team Lead, Complex Discharge Team, Alder Hey Children's Hospital</b></p>  <p>Complex Discharge  Team - North West F</p> <p>Anna enquired if a hub and spoke model, to help improve equality and provide support to DGH's was viable. Cathryn informed that the Alder Hey Complex Discharge Team work with local DGH's to share knowledge and processes. Cathryn added that collaborative working is essential to improve services across the region and invited anyone interested can contact her directly <a href="mailto:Cathryn.Livingstone@alderhey.nhs.uk">Cathryn.Livingstone@alderhey.nhs.uk</a>.</p> <p>Elaine O'Brien thanked Cathryn for her informative presentation and invited attendees to contact the ODN if they would like to present in the Excellence in Care section of a future Oversight meeting.</p>	CL
<p><b>6. Future Meetings</b></p> <p>Elaine O'Brien informed the group that although the ODN started with locality meetings, these would not be continued. Instead the ODN progress focused working groups with outcomes presented at quarterly Oversight meetings, dates for the Oversight meetings will be sent in due course. Jo McBride added that opinion will be sought from the Network on working group priorities. This will be sent out via email.</p>	EO
<p><b>7. Any Other Business</b></p> <p>Elaine O'Brien confirmed to the group that any updates, news and information received by the ODN would be shared to the Network via email. This may in the future be linked to the NW LTV ODN Website, once work on the website is complete.</p> <p>Elaine asked the groups opinion on parents presenting at a future Oversight meeting, the group agreed that there were no objections to this.</p> <p>Elaine O'Brien informed the group that remote ventilation training is being looked at as a pilot scheme. Alison O'Leary added that Train the Trainer courses could be restarted if needed and offered to be contacted for information.</p>	EO
<p><b>8. Next Meeting:</b>  TBC</p>	

### Actions

1. Review Terms of Reference and feedback comments
2. Share suggested contacts for meeting with ODN.

3. Agenda item for next NW LTV Oversight meeting – Transition of patients to adult services.
4. Email to be sent out for working group arrangement.

## **APPENDIX 1**

### **Attendees**

#### Network

Jo McBride, Network Director, NW LTV/PCC/SIC ODN's  
Elaine O'Brien, Lead Nurse, NW Paediatric LTV ODN's  
Stuart Wilkinson, Co Clinical Lead, NW LTV ODN  
Jo Birkmyre Project Support Officer NW Paediatric LTV/PCC/SIC/ ODN's

Helen Campbell, East Lancashire HT  
Stephenie Mielke, Claire House Children's Hospice  
Claire Palmer, Salford Royal FT  
Catherine Davies, WellChild  
Alice Drury, WellChild  
Jo Douglas, BCUHB  
Cathryn Livingstone, Alder Hey Children's Hospital  
Alison O'Leary, Alder Hey Children's Hospital  
Tracy Brooks, Courtyard Care  
Andrew Bentley, Wythenshawe Hospital  
Emma Sturt, Wigan Borough CCG  
Rachael Ellis, Alder Hey Children's Hospital  
Colin Dyer, WellChild  
Hannah Armah, St Helens and Knowsley TH  
Amanda Reed, Alder Hey Children's Hospital  
Fiona Price, Wirral University Teaching Hospital NHS Foundation Trust  
Helen Coutts, East Lancashire HT  
Christopher Bedford, Warrington And Halton Teaching Hospitals NHS Foundation Trust  
Michelle Brooks, Specialised Commissioning  
Anna Sibley, East Lancashire HT

### **Apologies:**

Graham Mason  
Jane Enright  
Mair Parry  
Anna Hughes  
Emma Twigg  
Tracy Drew  
Susie Holt  
Clare Halfhide