





North West ODN Oversight Group for Paediatric Long Term Ventilation

6th May 2022 13.30-15.30 Via MS Teams

MINUTES

	Item	Action
1.	<p>Welcome and Introductions</p> <p>Elaine O'Brien welcomed attendees to the meeting. The ODN team each introduced themselves.</p> <p>For attendance and apologies, please see appendix 1.</p>	
2.	<p>Update on how the Network is evolving</p> <p>Joanna McBride gave the following update presentation at the meeting:</p>  <p>ODN Update 6 May 2022.pptx</p>	
3.	<p>Review of patient numbers</p> <p>Presentation given by Dr Wilkinson:</p>  <p>ODN Patient LTV.pptx</p> <p>Presentation given by Dr Halfhide:</p>  <p>2022 Sleep and LTV ODN .pptx</p> <p>Presentation given by Elaine O'Brien:</p>  <p>May 2022 LTV cohort data.pptx</p> <p>The data shows a rapid increase in patient numbers. It was noted that sleep studies stopped during the Covid-19 pandemic, however they have now resumed and thus we are now seeing an upsurge in sleep disordered breathing being diagnosed. There was also the fact that people did not access healthcare during the pandemic, so there is now a catch-up effect. The same trend of patient numbers rising is also being seen across the country (there is no national body to monitor this, but this is being seen anecdotally by colleagues nationally).</p>	
4.	<p>Local and National Priorities</p> <p>Priorities going forward include:</p>	

	<ul style="list-style-type: none"> - Restart national LTV groups, and pull work together - Moving forward with national database - Consider GIRFT - Equipment standards - Monitor patient numbers - Delayed discharges - Changes in commissioning - Fuel and cost of living effect - Carer crisis - Level 2 pressures – keeping children close to home (recommendation – 4 beds per centre) 	
5.	<p>Local updates</p> <p>Update from Soraya Begum (Greater Manchester):</p> <ul style="list-style-type: none"> - Have 2 children in hospital who have been inpatients for a long period of time - Looking to recruit community care teams for these children - Looking at recruitment issues; including banding of staff (band 2/3, or would nursing associate be more appropriate), competency, pay and retention - Aiming to facilitate discharge as soon as possible - Also working on discharge for a Trafford patient - 24 NIV patients in community at present <p>Update from Lisa Harvey (Wales):</p> <ul style="list-style-type: none"> - 2 IV patients in Anglesey – private care providers commissioned - 1 IV patient in West Wales – No care package at present (private care provider withdrew), patient has collapsed. Looking to establish in-house team (band 4) <p>Update from Jane Enright (Blackburn/Burnley):</p> <ul style="list-style-type: none"> - No in-house carers, all are from external private agencies - Retention of staff is very problematic, but have no influence over this as they are private providers - Lot of time taken up by trying to manage problematic packages of care <p>Stuart Wilkinson queried the funding of care packages. Is there a standard arrangement for cost/hours attributed?</p> <p>Soraya explained that in Manchester her team look at the hours required, the level of care needed, and time needed from band 2/3/4 plus clinical oversight. The recommendations are considered, and the staffing costs are worked out using the midpoint of the band plus on-costs.</p> <p>Linda explained that recruitment of carers is an ongoing issue. It is not viewed as a long term career. There is a postcode lottery. We need to look at the North West picture and then wider. Where do we need band 2's, band 3's etc. We need to look at what training is available to them, retention and view being a carer as a career.</p> <p>Michele Brooks noted that each provider has a different tariff and works differently. Block contracts with NHS teams tend to be very expensive. Private providers range between being cheaper and more expensive. Retention is a big issue across the board.</p> <p>Facilitating discharge out of hospital is getting more and more difficult. It is very difficult from a commissioning point of view. There is no regulation around providers i.e. cost and how they contract their carers (they are often on zero hours contracts). If a team is secured, but then there are delays with housing etc, the team can be lost, then discharge is delayed further. Trying to increase marketplace around providers. Very difficult as can't forecast the future work needed from providers. This needs to be looked at nationally.</p>	

6. **How to include children and families in everything we do**

WellChild are to be key in children and families engaging with the network.

Update from Catherine Davies (Family Engagement Manager, WellChild) who was not present at the meeting:

Agenda Item:	Feedback:
Local and National Priorities	<p>Cost of living & fuel – in our WellChild Family Tree Network we have heard parents talking about the high cost of energy bills in particular, parents who children need medical equipment plugged in constantly have been talking about ways they and their carers can cut costs by asking if there are any machines that rather than charge daily, could be charged every other day instead e.g. suction machines/power banks. Are there any guidelines to help parents/carers understand what they could do/shouldn't do because of the risks? Also is anyone aware of any funding parents can apply to for help with energy costs and medical equipment – we're aware of the rebate help from suppliers if you have an oxygen concentrator and understand there have been calls to Gov to create a new energy grant for people with disabilities, we've not heard anything more about this if anyone else has?</p> <p>Carer Crisis parents are still talking about the ongoing struggle to recruit carers and the frustration around the expectation that parents will fill shift gaps in care. Some parents have referred to feeling pushed towards a Personal Health Budget (PHB) but although some report successes with this there is still difficulty in recruiting and PHBs can lead to families having more work/paperwork to do depending how this is set up. WellChild has been working on a care package survey that has been shared for a few months now, we put together some initial results of the survey and I have attached the presentation for you to see and share with attendees with minutes if you wish too. Key stats from this say:</p> <ul style="list-style-type: none"> - 61% of respondents say their care package is still not back to pre-covid levels 88% of respondents say there is an expectation from their care provider that they will cover ever more frequent staff shortages - 57% said the extra care responsibilities has had a negative impact on their mental health - 63% said it's had a negative impact on their physical health - 60% said it's had a negative impact on the time they spend with other members of their family - In a brief summary, respondents are saying they are exhausted, feeling like they are not valued, and there is no accountability, poor communication, and lack of involvement with parents in solutions, and there are no contingency plans in place <p>We have developed a 'New Deal' campaign which people can take a look at here: https://www.wellchild.org.uk/carecrisis/</p> <p>Approx. 80 families complete this, so it is a small data pool, but the survey is still live, so please share it with your families using the link above.</p> <p>We are currently looking at next steps for the campaign which are likely to be bringing some professionals around the table to talk together about ways we could address some of these issues. Anyone interested in finding out more about this please share their email address and we will be in touch.</p>

#SENDABetterMessage is a Disabled Children’s Partnership campaign WellChild are supporting on calling Government to use its SEND reform program to create a more, just fairer system of support for disabled children and families - one that is easier to navigate and gets them the services they're entitled to without the fight. This campaign aims to challenge this broken system and was launched shortly after the SEND Green Paper was published in March. The SEND Green Paper is a review that establishes a new national SEND and alternative provision system, setting nationally consistent standards for how needs are identified and met at every stage of a child's journey across education, health and care. There is a consultation period that is open now until the 1st July gathering feedback on the proposals and we hope the campaign will help parents, carers and young people especially get engaged and share their thoughts. The green paper sets out improvements for education and potentially could create more barriers for families. We are working with the DCP to ensure families understand what the Green Paper is and what it could mean, and how they can feed into the consultation which ends the 1st July.

How to include children and families in everything we do

Depending on your needs, WellChild is happy to support any family/youth involvement we can. We currently have a network size of 2,800 families all registered in the WellChild Family Tree and a really active parent and youth ambassador program. Recently we have supported other networks delivering surveys and focus groups to feed into LTV and SALT research, and open to discussions on what you would like. We have also just had Parent Ambassadors talk at a recent North Thames Paediatric Network board meeting about the importance of involvement with parents/youth and looking at their longer involvement with that network.

- Would you be looking for parent/Youth involvement in these meetings themselves, or in the workstreams coming out from these?
- You could look at recruiting some longer-term parent representatives in your workgroups, and even plan some smaller task groups/focus groups as projects arise.

Happy to chat more in a follow up call if you wish?

Presentation – Showcase piece

Are you able to share this presentation after the meeting, I would be really interested to see it. Our Information Officer, Callum, is working on a proposal to film some families talking about their LTV journey and experiences and it will be really insightful to see this and share with him if possible?

WellChild care package survey results presentation:







WellChild Care Package Survey Resu

Elaine O’Brien stated that she will catch up with Catherine Davies after the meeting regarding engaging with families, education and packages.

EO’B

Linda explained that with regards to bringing families together to a central point, in the past there have been difficulties with the practicalities and timing. We need to look at when and how the families want to engage and utilise technology such as Teams. WellChild have already done some work on this. Mid-morning is often a good time for families and via a virtual platform.

7.	<p>Work stream review and priorities</p> <p>Work plan review and priorities presentation:</p>  <p>LTV ODN Work Plan Review Spring Summ</p> <p>Comments on the work plan are welcome and can be forwarded to louise.king@mft.nhs.uk.</p>	
8.	<p>Working groups</p> <p>Elaine O'Brien explained that the initial focus for the working groups has been equipment and maintenance. The next step will be to look at education.</p> <p>Elaine also explained that she is linking in with other relevant groups in the region such as neonatal tracheostomy, paediatric critical care and palliative care. Elaine confirmed that there is representation included on this group from adult services for transition. Elaine also explained that she is joining national transition work. It is important to share learning nationally and not overlap work i.e. different groups focus on different aspects.</p>	
9.	<p>Risks</p> <p>Joanna McBride presented the ODN's risk register to the group:</p>  <p>Risk Register LTV.docx</p> <p>This is a draft version and any comments/additions are welcome and can be forwarded to louise.king@mft.nhs.uk.</p> <p>It was noted that we need to look to ensure we have the right level of engagement. For the data set we need to ensure that we are all using the same 'currency'. The carer crisis could be included under delayed discharges on the register.</p>	
10.	<p>Incidents</p> <p>Elaine O'Brien explained that with regards to incidents, there have been equipment issues such as tubes, cuffs and flanges breaking when still new. These have been flagged up. Also, the Philips recall is escalating, and this is likely to result in increased bed numbers this year.</p> <p>Elaine highlighted that it is important that all incidents across the region are flagged up for sharing and learning.</p>	
11.	<p>Moving forward</p> <p>Elaine shared the proposed oversight group attendees list:</p>  <p>Attendee list to the oversight group LTV</p> <p>Any comments and suggested additions are welcome and can be forwarded to louise.king@mft.nhs.uk.</p>	

	<p>Lisa Harvey queried whether the hospice in North Wales is to be linking in, as they are currently not supporting LTV children. Elaine stated that she will follow up on this.</p> <p>The group agreed that it would be useful to establish a hospice group to look at training, skills, competencies, tracheostomies etc.</p> <p>Elaine also suggested including representation from NWAS, NWTs, housing and social care.</p> <p>It was also noted that the group's Terms of Reference need to be re-visited and signed off at the next meeting.</p>	<p>E'OB</p> <p>EO'B</p>
	<p>Presentation – Showcase piece - The LTV pathway - A parent's experience</p> <p>A presentation was given by a parent, Laura, to share her experiences:</p> <p> LTV talk Waterhouse Slides.p</p> <p>Laura covered the following points in her talk:</p> <p>Communication/Support</p> <ul style="list-style-type: none"> - Parents & Doctors <ul style="list-style-type: none"> o LTV was on the front foot with communication results in less work overall. - Postcode matters/Community Support <ul style="list-style-type: none"> o Some community teams have closer links with the hospital o Meds – nearly resulted in 2 trips back to hospital - 6+ cases of food wasted. <ul style="list-style-type: none"> o Apparent delivery errors due to communication breakdowns. o Stored at a friend's house in the hope it would get used but had to be binned. - P-Pod – sat in storage for up to 2 months <p>Training</p> <ul style="list-style-type: none"> - Trachy and vent training from the same provider for parents and care package staff. - Our training was excellent in Hospital and efficient, but carers wasn't (very slow). <p>Care package</p> <ul style="list-style-type: none"> - Very time consuming to setup, large costly delays. <ul style="list-style-type: none"> o Needs advance planning but parents won't have enough experience to know this until it's too late. - Recruitment, the care package staffing was always on a knife edge, we didn't have many carers, but the agency still struggled to staff it. - Package break down's – care in hospital, loss of income for the carer, parking charges etc. - Support for carer's – we had one who couldn't cope with the situation. - Carer's in hospital provides stability for the child, especially on unfamiliar wards. <ul style="list-style-type: none"> o DBS checks <p>Local Hospital</p> <ul style="list-style-type: none"> - Not setup to deal with it. <ul style="list-style-type: none"> o Someone we know who works on one of the wards he'd have been admitted to said they weren't setup to deal with it. o Ambulance staff even said no point going to the local hospital. o couldn't leave the room to go to the toilet <p>Equipment/Finance</p> <ul style="list-style-type: none"> - Small Philips Neb – waste of Money <ul style="list-style-type: none"> o Tried to send it back unused and unopened but couldn't. o We had 3 stages with Ben <ul style="list-style-type: none"> ▪ Initial Stage – Needed O2 or he'd de-sat 	

	<ul style="list-style-type: none"> ▪ No need for O2, vent or nebs. ▪ Later, needed the vent so Neb ran from that. <p>- Pram switch – 2nd pram need due to vent but it did everything the first did and more, plus cheaper.</p> <p>Transportation</p> <ul style="list-style-type: none"> - Luckily, we had money to buy a car which wiped out all savings. - Stingray pram. Mid size car issues vs Large Estate vs 7-seater. <ul style="list-style-type: none"> o Different pram (Bug) different car. - Journey planning is critical <ul style="list-style-type: none"> o Suctions stops o Emergency laybys <p>OPTIONAL</p> <p>Parent Financing:</p> <ul style="list-style-type: none"> - Electricity – It’s direct costs of the vent, humidifier etc. - Indirect costs mount up, e.g. <ul style="list-style-type: none"> o 24-hour care means heating on 24 hours in winter o We had the room next to Ben’s setup like a 2nd living room. More electric costs etc o Hot weeks in summer required aircon or Ben couldn’t sleep. o Young children on vents don’t get mobility <ul style="list-style-type: none"> ▪ Swivel car seats help with tubes, suction, and positioning <p>Practicalities:</p> <p>Room setup matters:</p> <ul style="list-style-type: none"> - Bed in centre of the room - Space around limited - Hoovering – vent stand vs shelves - Concentrator near the window due to heat - Direction of tubing from the vent decides room layout - Aircon/dehumidifier <p>Flo Berquist asked if Laura would be willing to speak to her about her experiences, to help aid the training for new families. Laura agreed to this.</p> <p>Laura clarified that when she made journeys to the hospital unaccompanied, this was when her son just had a trachy. When he was ventilated, it was always two people that accompanied him to reduce the risk.</p> <p>The group thanked Laura for her time and for sharing her story. It was noted that there was a lot of learning from the fact that as her son’s condition got worse, the support seemed to get less.</p>	
	<p>Close</p>	

Appendix 1 – Attendance & Apologies:

Attendees:

- Network
- Jo McBride, Network Director, NW PCC/SIC ODN’s
 - Stuart Wilkinson, Co Clinical Lead, NW LTV ODN
 - Clare Halfhide, Co Clinical Lead, NW LTV ODN
 - Lucy Allton, Lead Nurse, NW SIC/PCC ODN’s
 - Elaine O’Brien, Lead Nurse, NW LTV ODN
 - Louise King, Project Support Officer, NW Paediatric Networks

Adam Davies, Clinical Educator, VAST Programme
Alice Drury, Charitable Programmes Project Manager, WellChild Charity
Alison O'Leary, WellChild LTV Nurse Specialist, Alder Hey
Anna Hughes, ANP for LTV, RMCH
Flo Bergquist, Parent Educator Nurse Specialist, Alder Hey
Gemma Saint, Consultant, RMCH
Jane Enright, Complex Needs Nurse and Equipment Lead, Pennine
Linda Partridge – Independent Member – Honorary Professor at Nottingham University
Lisa Harvey, Lead Nurse Technology Dependent Children, BCUHB
Lisa Wilby- Continuing Care Sister, Wirral NHS
Kirsten Wolffsohn- Consultant in Paediatrics Macclesfield General , East Cheshire NHS
Mair Parry, Consultant in Paediatrics, BCUHB
Meg Ruecroft- Specialist LTV Physiotherapist Alder Hey Children's NHS
Michele Brooks, Strategic Lead, Midlands Lancs Commissioning Support Unit, also covering Merseyside.
Michelle Wright- Head of Care, Zoe's Place Baby Hospice
Sam Torkington, Clinical Educator, VAST Programme
Shannon Smith, Clinical Educator, VAST Programme
Soraya Begum, Head of Service - Complex Children's Community Nursing Services, Manchester
Susie Holt- Consultant in Palliative Care, Alder Hey Children's NHS and Claire House Children's Hospice
Laura Waterhouse, Parent Representative

Apologies:

Emma Redmond, Emma Twigg, Andrew Bentley, Cathryn Livingstone, Anwen O'Leary, Sarah Jackson, Catherine Davies, Jemma Price