

## YORKSHIRE & HUMBER LONG TERM VENTILATION WORKING GROUP

### Agreed Actions 26 March 2019

	Actions	Lead	Timeline
1.	Parent and carer support groups and engagement – report on progress from Leeds and Sheffield at next meeting, and keep on agenda as rolling item	Rum Thomas Caz Maundrill Sharon Sloan	June 2019
2.	Circulate minutes from initial parent and carer focus groups to the LTV working group for information (NOT for website)	Sian Cooper	April 2019
3.	Data from Sheffield mapping exercise on whole numbers of LTV patients (NIV and tracheostomy) including breakdown of DGH patients to be sent to SC	Lee Richardson	April 2019
4.	Data from Leeds PICU on LTV patient numbers past 5 years including those being cared for in a level 3 critical care bed who are medically fit for discharge	Jo Lumsden	June 2019
5.	Acute pathway subgroup to look at whole pathway in Y&H for all LTV patients (NIV and tracheostomy) when acutely unwell or injured. <b>More representation needed (including DGH) and one or two to lead the group. Volunteers to SC please.</b>	Not yet named	April 2019
6.	Contact ambulance service to ask if could add “flag” on system for NIV patients as currently exists for tracheostomy patients	Sian Cooper	June 2019
7.	Offer educational session to Emergency Department in Leeds regarding LTV patients	Chris Edwards	June 2019
8.	Ethical framework for decision making in LTV – Leeds team to review current process and consider how it could be strengthened	Chris Edwards	June 2019
9.	Idea to develop online FAQ for parents and carers in the absence of 24/7 phone advice. CE to look into logistics and governance of doing this and report back at next meeting	Chris Edwards	June 2019
10.	Support for LTV business case in Leeds for West Yorkshire & Humber – (1) letter to Suzanne Abrahams from SC / KP on behalf of ODN summarising LTV parent focus group views and (2) minutes of this meeting to be sent to Suzanne Abrahams	Sian Cooper	April 2019
11.	Commissioning – email Emma Green setting out key issues and impact of commissioning barriers for LTV on children and families (CM/SG) and on PIC capacity (SC)	Caz Maundrill Sarah Georgiades Sian Cooper	April 2019
12.	Contact JR in Calderdale regarding carers / honorary contracts	Sian Cooper	April 2019
13.	Midlands Children’s LTV network conference flyer 25/6/19 at St Georges Hospital, Stafford to be sent to group	Karen Perring	April 2019
14.	Neonatal representative on group	Sian Cooper	April 2019
15.	Doodle Poll for next meeting in 3 months June 2019	Sian Cooper	April 2019