



13 July 2019

Dear Parents and Carers,

Re: Yorkshire & Humber Long Term Ventilation Working Group – feedback for parents and carers

We are writing on behalf of the Yorkshire & Humber Long Term Ventilation Working Group that we set up early in 2019. The group is working collaboratively to support the management of children requiring Long Term Ventilation in Yorkshire & Humber. The group has representation from all over the region and aims to improve equity of access to local and specialist services, ensure consistent standards across the region, and to facilitate the provision of safe, high quality care as close to home as possible for children on Long Term Ventilation.

We wanted to thank you for your contribution to the Parent and Carer Focus Groups held in Sheffield and Leeds last year and other patient feedback that we have received via the specialist teams. Your comments have helped us to know which areas we should be focusing on to improve outcomes including experience and quality of care for patients. We also thought you might like to know how your feedback has influenced the work of the group and what we still want to achieve in the future.

Some of the things that members of the group have done since 2019 are:

- Parent and carer focus groups held in Leeds and Sheffield – themes discussed included aspirations for general support and advice; community care teams, equipment and training; experiences of acute illness and injury; discharge planning and transition to home
- Strengthening relationships and sharing of good practice between units
- Mapping of all patients in Yorkshire & Humber to identify education and training needs of individual hospitals
- Data collected on paediatric critical care bed days to help inform commissioners when planning services including appropriate step-down areas and discharge planning
- Written to Leeds Children's Hospital to strongly support business case for expansion of their Long Term Ventilation Service
- Introduced the Leeds Carer Policy to Leeds Children's Hospital to enable community carers to work in the hospital on honorary contracts which led to earlier discharge home

- More access to education via Leeds Children's Hospital including educational session for Emergency Department staff, wider access to monthly ventilation workshops for all staff, and drop-in Basic Life Support sessions for families
- Held a one-day educational event for professionals in Yorkshire & Humber on Long Term Ventilation which included talks from experts, sharing examples of local good practice, and a practical workshop
- Worked with commissioners to fully understand the key issues and impact of commissioning barriers on children and their families

What we are still working on:

- A consistent pathway in Yorkshire & Humber for all acutely unwell or injured children on Long Term Ventilation
- Online FAQ (frequently asked questions) for parents and carers
- Minimum standards of care document for private care agencies
- Engaging with Clinical Commissioning Groups and NHS England Specialised Commissioning who have set up a Task and Finish Group for Long Term Ventilation with oversight by the Children's Hospital Partnership Board for Leeds and Sheffield
- Engagement and collaboration between all relevant services to work towards the recommendations set out in the National NCEPOD Long Term Ventilation Study published in 2020

We hope that our working group will achieve as many of these aims as possible and want to thank you once again for your contribution. If you have any comments or questions about this work, please direct them through your local specialist nurse or consultant in Long Term Ventilation, who will be able to feed back to the group on your behalf.

With kind regards,



Sian Cooper
Clinical Lead (North)
Y&H Paediatric Critical Care ODN



Karen Perring
Network Manager & Lead Nurse
Y&H Paediatric Critical Care ODN