

Thames Valley Long Term Ventilation Pathway and Standards of Care for Children

First Edition

December 2018

**Every child in the Thames Valley with long term ventilation needs
will spend no longer in hospital than medically necessary
and will receive safe, high quality care in the community**



Thames Valley Children's
Palliative Care Network

Oxford

**Patient
Safety
Collaborative**

Thames Valley Long Term Ventilation Pathway and Standards of Care for Children

Authors

Helen Bennett, Director of Care, Alexander Devine Children's Hospice Service
Andrea Lambert, Head of Children's and Family Services, Rennie Grove Hospice Care
Karen Brombley, Nurse Consultant, Helen and Douglas House

Consultation Group

Emily Harrop, Consultant in Paediatric Palliative Care, Helen and Douglas House, Oxford
Geri Briggs, Patient Safety Manager, Oxford Patient Safety Collaborative, Oxford Academic Health Science Network
Jeremy Hull, Consultant Paediatrician, Respiratory Medicine, and Jayne Gallagher, Paediatric Respiratory Advanced Nurse Practitioner, Oxford University Hospitals NHS Foundation Trust
Claire Turnbull, Operational Manager Children's Community Nursing Service, Oxford Health NHS Foundation Trust

The consultation group collaborated to review all drafts of the document with additional contributions from health care professionals representing NHS and non-statutory services both locally and nationally.

Acknowledgements

The development of this pathway would not have been possible without support and feedback from a number of people. We are grateful to all those who have commented on various drafts and contributed to discussions and to all those who have shared their practice experience of caring for children and young people requiring long term ventilation. The standards adopted by the Thames Valley Network have been informed by the West Midlands Quality Standards ⁵, the NHS England Paediatric Long Term Ventilation Service Specification ⁷ and NHS Outcomes Framework ⁶. They are aligned to the Hospital to Home LTV Discharge Pathway (Royal Brompton & Harefield Hospital)⁴ which is used at Oxford University Hospitals NHSFT.

This pathway is relevant and developed for all children who have long term ventilation requirements. It is acknowledged that many of these children are not life limited.

The Thames Valley Children's Palliative Care Network

The Thames Valley Children's Palliative Care Network (TVPCN) was established in 2009 to support children with a life limiting or life threatening condition and their families across the region. It brings together professionals working in Health and Social care and education to support the strategic and operational development of children's palliative care.

Correspondence

To Sue Lakie, TVPC Network Administrator doctorsinternal@helenanddouglas.org.uk

Disclaimer

Whilst great care has been taken to ensure the contents of this document are correct and up to date, the authors cannot guarantee the documents accuracy or completeness. Readers should take responsibility to verify information and any changes in law and practice.

Distribution and Use

This document may only be reproduced with the permission of the Thames Valley Children's Palliative Care Network using all appropriate acknowledgements.

Table of Contents

Overarching Statement	1
1.0 Scope and Purpose	1
2.0 Definitions	2
3.0 Pathway of Care	3
4.0 Outcomes of care	5
4.1 Local outcomes	5
4.2 Measurables	5
5.0 Standards of care	6
5.2 Personalised care planning	9
5.3 Re-assessment and review	10
5.4 Sufficient, skilled and competent staff	10
6.0 Ethics and decision making	13
7.0 Commissioning	14
8.0 Audit and Evaluation	14
9.0 References	15
10.0 Clinical guidance and training resources	16
11.0 Appendices	16
Appendix 1 Ventilatory Care Template	17
Appendix 2 – Audit/Evaluation Template Form	19

Overarching Statement

Every child in the Thames Valley with long term ventilation needs will spend no longer in hospital than medically necessary and will receive safe, high quality care in the community.

This means all children will have:

- A manageable and effective pathway of care
- A personalised care plan
- Access to education and enrichment activities
- Care delivered by trained and skilled staff
- Fewer unnecessary admissions to hospital

1.0 Scope and Purpose

This document sets out the standards of care required for children with long term ventilation (LTV) needs who are cared for in the community. With increasing numbers of children and young people (CYP) who require long term ventilation there is an urgent need to establish standards to support better outcomes of care. This requires a skilled workforce to provide care, with flexibility to work across settings and organisational boundaries.

The aim of the document is to outline a pathway of care (fig 1, page 4) and define standards of care that will support discharge from hospital to home and the continued care of children and young people in the community. This will include, as appropriate for some children, transition to adult services and palliative and end of life care.

Standards of care will provide guidance to improve the outcomes and experience for children and young people who require ventilation in the community. The document will serve as a reference for Clinical Commissioning Groups (CCGs) who are responsible for the assessment of a child's additional health needs and ensuring an appropriate package of care. The pathway applies to all children and young people with long term invasive and non-invasive ventilation across the Thames Valley.

2.0 Definitions

Long term ventilation (LTV) can be defined as “any child who, when medically stable, continues to require a mechanical aid for breathing after an acknowledged failure to wean, or slow wean, three months after the institution of ventilation.”¹ (Jardine & Wallis 1998). Most of these children require a high complexity of care after discharge from hospital to the home setting.

In this document the terms child and children refer to any baby, child or young person from birth to 18 years of age.

The 2016 Department of Health National Framework for Children and Young Peoples Continuing Care ² suggests the following definitions of need in relation to LTV use.

Description	Level of need
Supportive but not dependent non-invasive ventilation which may include oxygen therapy which does not cause life-threatening difficulties if disconnected	Moderate
Requires high flow air / oxygen to maintain respiratory function overnight or for the majority of the day and night; or is able to breathe unaided during the day but needs to go onto a ventilator for supportive ventilation at night. The ventilation can be discontinued for up to 24 hours without clinical harm;	High (Level 1)
Requires ventilation at night for very poor respiratory function; has respiratory drive and would survive accidental disconnection, but would be unwell and may require hospital support.	Severe (Level 2)
Unable to breath independently and requires permanent mechanical ventilation; or has no respiratory drive when asleep or unconscious and requires ventilation, disconnection of which could be fatal; or a highly unstable tracheostomy, frequent occlusions and difficult to change tubes.	Priority (Level 3)

3.0 Pathway of Care

The pathway of care for children with LTV includes discharge from hospital to home with continuity of safe and high quality care in the community (fig. 1). It includes family support, play and psychosocial support. A range of services and collaborative multi-professional working is needed to support the seamless pathway of care for children who require LTV ³ (Ray et al 2018).

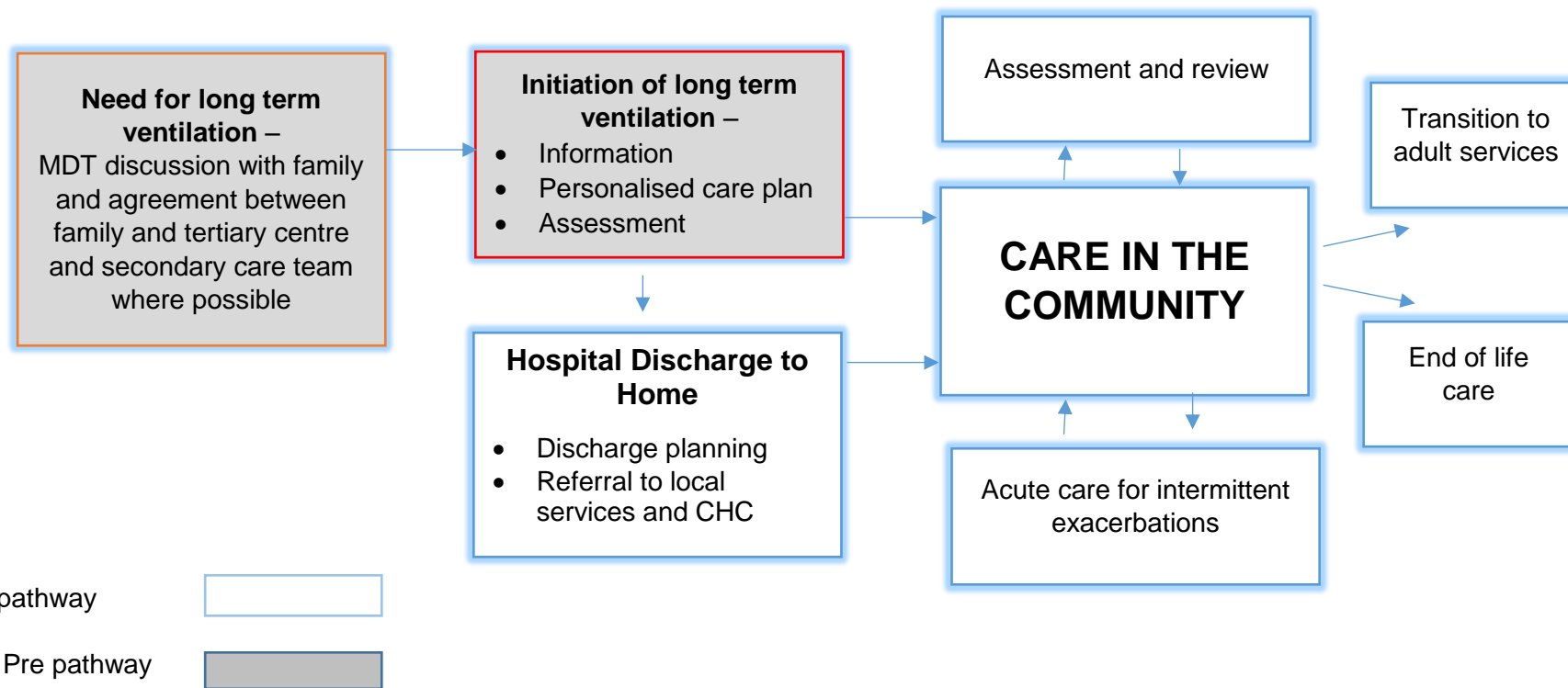
The decision to commence LTV will nearly always be made in a tertiary hospital and the paediatric respiratory unit is responsible for identifying children with LTV needs. An ongoing consistent approach to care is best achieved via a core group of clinical professionals. This should include the acute care/current care consultant, the respiratory consultant who will follow-up the child in the long term and a member of the local paediatric team who will be the first port of call for the family.

Once the child is clinically stable and fit for discharge other relevant team members will be present to provide information and support discharge planning. Non-medical team members such as acute and specialist nurses, physiotherapists, play therapists and psychologists should be represented. There should be appropriate assessment and referral to local services with timely Continuing Care assessment. In some cases, palliative care should also be represented to provide that vital interface with advance care planning when life limitation is anticipated ³ (Ray et al 2018).

Discharge from hospital to home supports complex hospital discharge through a comprehensive pathway of care. All children within the Thames Valley should be on the children's LTV pathway (Royal Brompton and Harefield Hospital ⁴). The pathway supports health care professionals with the discharge process and aims to improve communication and provide a partnership approach to a child's management. The pathway will vary according to the child's needs however, all children will require an appropriate package of care, suitable housing and provision of trained and competent carers.

Once in the community setting at home, respite or school, all children and young people with LTV needs require safe, high quality care delivered by skilled and competent staff. Ongoing support will provide comprehensive care planning, assessment and review. The pathway signposts routes for readmission to acute care and highlights the path for some families to transition to adult services and where necessary, how to access palliative and end of life care.

Fig 1. LTV Pathway of Care



(Adapted from West Midlands LTV Network 2015 ⁵)

4.0 Outcomes of care

Local outcomes are aligned to the NHS England Outcomes Framework ⁶ and integrate the minimum standards highlighted from West Midlands LTV standards ⁵ and NHS England Paediatric Long Term Ventilation Service Specifications ⁷.

Domain 1	Preventing people from dying prematurely	Yes
Domain 2	Enhancing quality of life for people with long-term conditions	Yes
Domain 3	Helping people to recover from episodes of ill-health or following injury	Yes
Domain 4	Ensuring people have a positive experience of care	Yes
Domain 5	Treating and caring for people in safe environment and protecting them from avoidable harm	Yes

4.1 Local outcomes

- Children and young people will have safe and effective care from hospital to home (Domain 3)
- Children and young people will have a personalised care plan (Domain 2)
- Children and young people will lead independent lives as possible in the community including access to education and social opportunities (Domain 2)
- Children and young people will have a positive experience of care (Domain 4)
- Standards of care will be implemented keeping children safe and free from harm (Domain 5)
- Children and young people will receive adequate and safe care through transition from child to adult services (Domain 4)
- Children and young people and/or parents and carers will be actively involved in choices about place of care at the end of life (Domain 4)

4.2 Measurables

- Children would spend no longer in hospital than medically necessary
- All CYP would have a personalised care plan including a ventilation prescription
- A decrease in unplanned admissions
- All children are cared for by trained and competent staff
- Improved parental and CYP satisfaction

5.0 Standards of care

The standards adopted by the Thames Valley Network have been informed by the West Midlands Quality Standards ⁵, the NHS England Paediatric LTV Service Specification ⁷ and NHS Outcomes Framework ⁶. They are aligned to the Hospital to Home LTV Discharge Pathway (Royal Brompton & Harefield Hospital) ⁴ which is used at Oxford University Hospitals NHS Foundation Trust (OUH).

Standards of care:

1. Information - services, equipment and keyworker
2. Personalised care planning
3. Re-assessment and review
4. Sufficient and skilled and competent staff

The agreed standards should be integrated into organisations governance framework for quality care to ensure safe and effective practice.

5.1 Information

Children, young people and families should be given verbal and written information that includes:

- Ongoing information of their condition and its impact
- Knowledge of equipment including how to use it, preventing problems and what to do if they occur, maintenance and storage and how to return equipment when no longer needed. This information may be in the form of a User Guide or Manual.
- Details of medication, including what it is for, when to take it, storage and possible side effects and when to review
- Management of acute and chronic changes in health
- Lifestyle advice, including nutrition, exercise and travel
- Housing and housing adaptations
- Emotional, spiritual and psychological support for children and young people themselves and for their families, including siblings
- Benefits advice, Personal Health Budgets and how to access charitable and voluntary sector resources
- Transport and mobility
- Other local services available for children with complex care needs and how to access them
- Discussion of advance care planning (as appropriate)

- Relevant voluntary organisations and support groups
- Where to go for further information, including useful websites

Services available

Children, young people and families should have access to appropriate services 24 hours a day, 7 days a week. Families should be given verbal and written information about the services available to support them including:

- What the service provides
- Staff and facilities available
- How to contact the service for help and advice, including 'out of hours'

Timely access to the following services should be available:

- Pharmacy advice
- Community paediatrician
- Open access to local District General Hospital (DGH) children's ward, in line with local policy as appropriate
- Respiratory physiology, lung function tests and sleep studies
- Assessments for housing adaptations
- Wheelchair assessment, supply and maintenance service (if required)
- Continence services (if required)
- Play and Psychological Support
- Speech and Language Therapy (SALT)
- Interpreter services
- Patient Advice and Liaison Service (PALS) and how to make a comment, compliment or complaint
- Spiritual support
- Health Watch or equivalent organisation
- Agreements with Local Education Authorities should be in place covering responsibilities and arrangements for ensuring children and young people with continuing care needs have timely and robust support to fulfil their educational potential. There should be an Education, Health and Care Plan (EHCP) in place which clearly identifies how the child's health needs are met.

Equipment

Suggested equipment requirements:

Child with level 1 need (non-tracheostomy):

- One ventilator in the home
- Access to a replacement ventilator within 24 hours
- Oxygen Saturation monitor to be used at night for children wearing full face mask

Child who is ventilator dependent (level 2 or 3):

- Two ventilators including internal and external battery backup
- The required oxygen prescription
- Two oxygen saturation monitor and robust arrangements for replacement within 12 hours
- Self-inflating bag/ambu-bag
- Two sets of suction equipment
- Two sets of appropriate humidification equipment
- Access to a mobile phone and to a land line in the home (or back up mobile)
- Equipment needed for tracheostomy care
- Height adjustable (profiling) bed or cot
- Supply of consumables
- Call / listening system

As part of the needs assessment and preparation for home the following will also need to be considered

- Back up lighting
- Adequate seating for care staff
- Adequate number of electrical points
- Appropriate storage for equipment and consumables
- Facilities for delivering medicines at home
- Push chair or pram suitable for carrying ventilation and suction equipment

Safety, availability and suitability of equipment

An Equipment Policy should be in use covering responsibilities and arrangements for:

- Setting up equipment
- Maintenance and servicing of equipment
- Emergency replacements
- Replacement of breakages
- Emergency contact details
- Return of equipment when no longer needed

Keyworker

Each child should have a named tertiary and community paediatrician and an identified keyworker based in the community (usually a Community Children's Nurse (CCN)) who will be introduced to the family during the discharge process. The keyworker will ensure liaison with the tertiary respiratory nurse, community paediatricians and other local services, including education and housing services.

The key worker will have responsibility for:

- Maintaining regular contact with the child and their family and providing information, support and advice.
- Liaison with the child's named community children's nurse
- Keeping relevant documentation up to date, including the personal care plan, the advance care plan, and the education health care plan.
- Ensuring all carers have up to date evidence of competence for their role in the child's care. All carers are required to undertake an annual competency assessment (see below).
- Carrying out relevant risk assessments. This will include risk assessments for when children are cared for outside their usual home environment – for example when they stay with other relatives, when they are on holiday and when they attend respite or hospice facilities.
- Informing other services involved with the child about changes to their condition or plan of care.
- Informing the child's school of changes to their condition or plan of care.
- Initiating a multi-disciplinary care planning meeting in order to review the child's plan of care if this is needed before the next planned review date.
- Participating in multi-disciplinary discharge planning.
- Consideration of and acting on safeguarding issues.

5.2 Personalised care planning

Each child should have a comprehensive care plan that includes

- Risk assessments
- Ventilator prescription
- An individualised care plan for ventilation
- An escalation plan
- Equipment

- Advance care plan (as appropriate)
- A description of the equipment the child uses
- Key contacts
- Detailed care plans (where appropriate) for
 - Tracheostomy care
 - Oxygen delivery
 - Suction
 - Humidification

Normal observations of the child, the ranges and limits, must be recorded within the care plan. All care plans and equipment should be checked at the start of each carer's shift. (Example Ventilatory Care Plan template can be seen in Appendix 1).

5.3 Re-assessment and review

All children requiring LTV should have a comprehensive assessment and planned formal review. For children with level 2 or 3 needs this is likely to occur at a frequency of not less than 3 - 6 monthly and will usually include an overnight sleep study to assess ventilation requirement.

The CCG will undertake regular review of the care package. Reports from professionals caring for the children or young person will be needed to support these reviews.

Personal health care plans, escalation plans and advance care plans all need to be kept up to date and reviewed when there is a change in the child's circumstances, and not less frequently than annually. It is recommended that a review check list is completed no less frequently than every 12 months. This should be completed by the LTV nurse and community-based key worker.

5.4 Sufficient, skilled and competent staff

All practitioners caring for children with LTV needs must be competent and confident to provide the appropriate level of care and have been assessed and signed off as having that level of competence. There should be a skilled and sufficient workforce surrounding the child in all settings. All services should be responsible for monitoring the levels of skilled and competent staffing.

Training

The training and competence of those caring for children on LTV is essential to ensure the delivery of safe, high quality care. This includes access to and engagement in clinical supervision appropriate to staff roles.

Training should be appropriate for the individual child. It should take account of Nursing and Midwifery Council (NMC) guidance on responsibilities of nurses and carers and the delegation of health care tasks.

All staff must undertake a one or two-day theory training and practical training on an annual basis, delivered by a competent and skilled practitioner with a training qualification or train the trainer level of expertise. All staff must also undertake individual learning and development to be able to achieve competence in practice.

It is recommended that all carers involved with Level 2 and 3 children ventilated via a tracheostomy are trained, assessed and monitored according to the Joint Competency Document for Carers Working with Long Term Tracheostomy Ventilated Children (June 2017) Royal Brompton and Harefield NHS Foundation Trust and Great Ormond Street Hospital for Children Foundation Trust. The most recent version of the document should be sought from the Respiratory Nurse Specialist at the tertiary hospital.

For Children who are already established in the community and have not been registered on The Hospital to Home Pathway, the Respiratory Team at the Tertiary Hospital will provide an up to date version of the Competency Document to be used by community services.

Individual training specific to the child and young person is also essential to support safe practice. Whatever prior training a practitioner has had, they must be assessed as competent to care for the specific child that they will be responsible for. This assessment needs to be carried out by a trained and competent nurse who is familiar with the specific child's health care needs and should be carried out with reference to an up-to-date personalised care plan for that child.

Specific ventilation courses should meet the required standards for theory training and further practical training supported by the individual organisation/service.

Clinical guidance and further resources are suggested in Section 10 'Clinical Guidance and training resources'

Training will be carried out by a competent and skilled practitioner and should cover:

- Anatomy and physiology
- Tracheostomy care

- Suctioning
- Ventilation, including Non-invasive ventilation
- Care of the ventilated child via tracheostomy
- Humidification
- Oxygen
- Equipment
- Assessment and monitoring
- Emergency procedures
- Paediatric Life Support
- Knowledge of medications
- Health and Safety
- Risk of Infection
- Risk management

Mandatory training for safeguarding, lone working, transporting children, advanced communication and end of life care should be included as part of all learning and development of staff working with children and young people in the community.

Competence

All staff caring for children requiring LTV must achieve and maintain an annual basis LTV competence (see fig. 2).

Assessment and sign off must be undertaken by a skilled and competent LTV practitioner identified within an organisation – this could be a Clinical Nurse Specialist (CNS), Practice Educator or Senior Nurse. Signed evidence of competence dated within the last 12 months must be held by all staff caring for children and young people with ventilation requirements.

Each service should have a competency framework informed by the Joint Competency Document for Carers Working with Long Term Tracheostomy Ventilated Children (June 2017) Royal Brompton and Harefield NHS Foundation Trust and Great Ormond Street Hospital for Children Foundation Trust. The most recent version of the document should be sought from the Respiratory Nurse Specialist at the tertiary hospital.

The framework should state the competencies required for specific roles and a training plan that provides details of how and when competencies should be achieved and maintained.

Competencies should cover

- Care of a children requiring LTV that includes understanding the purpose of supportive ventilation

- use of all equipment and emergency procedures
- Tracheostomy care
- Humidification
- Oxygen and saturation monitoring
- Suctioning
- Resuscitation
- Safeguarding
- Infection control and disposal of clinical waste
- Medicines Management
- Professional boundaries
- Risk management

Other relevant competencies meeting the individual needs of the child must be achieved e.g. naso-gastric care and gastrostomy care.

Fig.2 Process of competency achievement and maintenance of competence



(Adapted from EACH 2017 ⁸, with permission)

Clinical Supervision

All staff caring for children on LTV should engage in clinical supervision which should take place at least quarterly. This should involve opportunity to reflect and learn from clinical practice and should include issues of best practice and safeguarding.

6.0 Ethics and decision making

The choices associated with LTV may involve complex decision making and raise ethical concerns about children’s interests, parental decision making and health care costs. Understanding all views and perspectives is important as part of the decision making process and finding opportunities for shared decision making involving the child, parents and health care professionals is essential ³ (Ray et al, 2018)

7.0 Commissioning

This pathway provides information to help commissioners assess and understand the needs of children on LTV across the Thames Valley. It will support the improvement of service quality and provide assurance of the quality of local services.

Use of long term (more than 3 months) ventilation, either via a mask interface (also called non-invasive ventilation, NIV) or via a tracheostomy, is recognised as an additional health care need by the National Framework for Children and Young People's Continuing Care 2016 ². It describes how CCGs are responsible for making an assessment of a child's additional health care needs and then developing and commissioning an appropriate package of care. It recognises that CCG assessors will need information and support from other professionals in order to complete an assessment. The CCG is also responsible, via its performance or assurance team, for ensuring that the quality of the package is appropriate for the child's needs and that the quality care is maintained.

Commissioned services should include

- Step down
- Short breaks
- Home support services
- Support to access education

8.0 Audit and Evaluation

All services should have a programme of audit and evaluation that includes document control of care plans, risk assessments, policies and Standard Operating Procedures.

Each service should set local key performance indicators to measure for quality and improvement and compliance with clinical standards. These may include measures of case load activity, access and response, care planning, access to a named keyworker, training and staffing.

Regular feedback from children and families is expected to inform service development and to measure achievement of outcomes. (See appendix 2)

9.0 References

1. Jardine E & Wallis C (1998) Core guidelines for the discharge home of the child on long-term assisted ventilation in the UK. Thorax 53. P.762-767.
2. Department of Health (2016) National Framework for Children and Young Peoples Continuing Care. DH.
<https://digital.nhs.uk/data-and-information/publications/ci-hub/nhs-outcomes-framework>
3. Ray S, Brierley J, Bush A et al. Arch Dis Child Epub ahead of print, accessed 21.09. 2018 DOI: 10.1136/archdischild-2018-314997
4. Royal Brompton Hospital - <http://rbht.nhs.uk/healthprofessionals/clinical-departments/paediatrics/childrens-long-term-ventilation-service/>
5. West Midlands Quality Review Service – Quality Standards – Services Providing LTV for Children and Young People
<http://www.wmqrs.nhs.uk/quality-standards/published-standards>
6. NHS England Outcomes Framework
<https://digital.nhs.uk/data-and-information/publications/ci-hub/nhs-outcomes-framework>
[accessed May 2018](#)
7. NHS England (2015) Paediatric Long Term Ventilation Service specification.
<https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/01/e07-spec-paedi-long-ventilation.pdf>
8. East Anglia Children's Hospice
<http://www.each.org.uk>

10.0 Clinical guidance and training resources

1. NICE End of life care for infants, children and young people with life-limiting conditions: planning and management. <https://www.nice.org.uk/guidance/ng61>
2. Royal Brompton Hospital - <http://rbht.nhs.uk/healthprofessionals/clinical-departments/paediatrics/childrens-long-term-ventilation-service/>
3. University Hospital Southampton. Transition to Adult Services: Ready Steady Go <http://www.uhs.nhs.uk/OurServices/Childhealth/TransitiontoadultcareReadySteadyGo/Transitiontoadultcare.aspx>
4. West Midlands Quality Review Service – Quality Standards – Services Providing LTV for Children and Young People <http://www.wmqrs.nhs.uk/quality-standards/published-standards>

11.0 Appendices

Appendix 1 Care Plan Template

Appendix 2 Audit Form

Appendix 1 Ventilatory Care Template	Details / Comments				
<p>I need this equipment to help me breathe: (Type of Ventilator according to level of dependency)</p>					
<p>Level of ventilatory support</p>	<p>Level 1 – The child is able to breathe unaided but needs supportive ventilation</p>	<p>Level 2 – The child requires ventilation at night</p>	<p>Level 3 – The child is unable to breathe independently</p>		
<p>The ventilator machine was last serviced:</p>					
<p>Equipment checked on each visit: (use checklist)</p>	Sign		Date		
<p>My ventilator attachments: (list all attachments...)</p>					
<p>Care of my ventilator machine: (include cleaning, charging, filters, ...)</p>					
<p>Oxygen / suction / Humidification (please use separate detailed care plans)</p>					

Set-Up & Use	Details / Comments				
<p>Times of ventilator support (consider 24 hours, when tired, overnight...)</p>					
<p>The ventilator is attached by: (consider mask, tracheostomy,)</p>					

Appendix 2 – Audit/Evaluation Template Form

Criterion		Number	%
Number of LTV children			
Ventilator dependency 1. Less than 6 hours day/night 2. Night time 3. More than 18 hours			
Ventilation	Mode 1. CPAP 2. Non invasive ventilation (BiPaP) 3. Invasive ventilation via tracheostomy 4. Other respiratory support		
	Oxygen Via ventilator or breathing spontaneously		
	Humidification		
Care package in place			
Equipment list in place			
Discharge planning meeting held			
The family were provided with information about all relevant services			
Each child has a clear, personalised care plan			
Escalation plan			
Appropriate risk assessments • Tracheostomy • Ventilation • Humidification			
Ventilator Prescription			
Qualified LTV staff			
Staff attendance at (annual) training			
Staff competencies reassessed annually			
Staff attendance at supervision			

Completed by.....Date:.....