

# Quality Standards

Services providing

Long-Term Ventilation

for Children and Young People

Version 4.3

July 2021

**These Quality Standards were developed in accordance with the International Standard ISO/IEC 17020:2012 - Conformity assessment – Requirements for the operation of various types of bodies performing inspection in line with our accreditation with UKAS as an Inspection Body (No 8831).**

**The Quality Review Service closed on 31<sup>st</sup> July 2021, UKAS have asked that the accreditation symbol now be removed.**

**The standards can be used until they reach their expiry date – October 2021.**

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V2	17.12.13	Revised version
V3	02.04.15	Incorporating national comments
V3.1	09.02.16	Paragraph added about organisation's clinical governance arrangements UKAS accreditation logo added
V4	10.10.18	Revised. Incorporating comments from the Midlands Children's Long-Term Ventilation Network, in particular reflecting the increased role of allied healthcare professionals in the care of children needing long-term ventilation.
V4.1	20.04.20	Rebranding to QRS
V4.2	23.11.20	<ul style="list-style-type: none"><li>• QRS Contact details amended.</li><li>• Added in addition to CQC that other regulatory frameworks are in use in the devolved nations.</li><li>• QS PP- 601 amended to include use of systems and governance arrangements for virtual consultations</li></ul>
V4.3	31.07.21	UKAS logo removal

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## Introduction

The number of children and young people in the UK requiring long-term ventilation has increased significantly in recent years, from one in 1975 to 24 in 1988, 141 in 1998 and 933 in 2010<sup>1</sup>. Noyes (2006, p.8) highlighted the human costs of long-term ventilation and found significantly lower health-related quality of life in long-term ventilated children. Parents also identified consequences to long-term hospitalisation of their children including reduced communication, concentration and confidence. Signs of institutionalisation in children's behaviour have also been identified by parents, including shyness and a lack of a sense of belonging (Noyes, 1999, p.446). Linahl and Lindblad (2011) highlighted that limited available time affected the inclusion of families in their work and community with lack of formal care packages being a major contributory factor. Children and young people's thoughts around health and the restrictions of long-term ventilation can identify the extreme frustration felt by some children, for example 'it makes me feel like some kind of dog, chained out in the front yard' (Linahl, Lindblad 2011, p.252).

Children and young people on long-term ventilation require the most complex care that is given outside a hospital environment and there are significant risks involved in looking after a child on long-term ventilation in the community. Supporting these children to live as normal a life as possible at home with their families brings many benefits and any risk involved must be balanced against the benefit to the child of being at home rather than in hospital long term. All risks must be fully assessed, understood by the family and managed appropriately. A balanced approach to risk management is needed if children and young people are to take advantage of the quality of life, educational, social and developmental opportunities of living in the community. Their care must be of the highest possible quality "in a child-centred environment, by staff trained in caring for children" (*Learning from Bristol. The Report of the Public Inquiry into children's heart surgery at the Bristol Royal Infirmary 1984-1995*, Ian Kennedy, July 2001, p2). "Lack of training in treating children and young people may lead staff to treat them inappropriately, however unintentionally. This includes not recognising children's different clinical needs, or not engaging with them in an age-appropriate way or, for younger children, not engaging with their parent or carer appropriately." (*Getting it Right for Children and Young People – A Review*. Professor Ian Kennedy, 2010).

These Quality Standards aim to improve the quality of services for children and young people needing long-term ventilation. The Standards help to answer the question: "For each service, how will I know that national guidance and evidence of best practice have been implemented?" The Quality Standards are consistent with NHS England's Service Specification E07/S/c 'Paediatric Long-Term Ventilation' and are suitable for self-assessment, monitoring by commissioners and use in peer review visits. They describe what services should be aiming to provide and all services should be working towards meeting all applicable Quality Standards within the next two years.

These standards were reviewed by the Midlands Children's Long-Term Ventilation Network (MCLTVN) (Appendix 1a) in 2018 in recognition of the increasing allied health professional representation at the MCLTVN. This latest version therefore recognises and reflects the developing role, involvement and importance of allied health professionals in the care of children and young people needing long-term ventilation.

The Standards were initially developed by a Sub-Group of the Midlands Children's Long-Term Ventilation Network with input from Dr Andrew Selby, Consultant in Paediatric Intensive Care and Long-Term Ventilation, Alder Hey Children's NHS Foundation Trust and the North West and North Wales Paediatric Long-Term Ventilation Network and Elspeth Jardine, Ventilation Service Coordinator, NHS Greater Glasgow and Clyde. The Standards were subsequently revised by a national Pathfinder Working Group (Appendix 1b) and circulated nationally for comment. The Standards therefore build on work undertaken in various parts of the country. The standards were then adopted nationally by NHS England in their revised Service Specification E07/S/c 'Paediatric Long-Term Ventilation' (2015)<sup>2</sup>. The Quality Standards are based on and support implementation of national strategies and guidance, including NICE guidance and Quality Standards. Appendix 3 lists relevant national guidance and links it to each of the Quality

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<sup>1</sup> 1975 and 1988: Robinson (1990), 1998: Jardine et al (1999) - All cited in Noyes (1999) p. 441. 2010: Wallis et al (2011)

<sup>2</sup> Available at: <https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/01/e07-spec-paedi-long-ventilation.pdf> [Accessed 02.07.2018. Undated but believed to be 2015]

Standards. Appendix 4 cross-references each of the Quality Standards to the British Standards Institution PAS16:16 and the Care Quality Commission Key Lines of Enquiry.

We hope that through the Quality Standards and, at some future date, a peer review programme, the quality of services providing long-term ventilation for children and young people will improve and in particular:

- a. Children and young people who need long-term ventilation, and their families, will know more about the services they can expect.
- b. Commissioners will be supported in assessing and meeting the needs of their population, improving health and reducing health inequalities, and will have better service specifications.
- c. Service providers and commissioners will work together to improve service quality.
- d. Service providers and commissioners will have external assurance of the quality of local services.
- e. Reviewers will learn from taking part in review visits.
- f. Good practice will be shared.

Service providers and commissioners will have better information to give to the Care Quality Commission and NHS England / Improvement.

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## Aims of the Quality Standards

The Quality Standards aim to improve the quality of the Long term ventilation for children and young people 'pathway' and to help answer the question: "At each point on the pathway, how will I know that national guidance and best practice have been implemented?" The Quality Standards are suitable for use in self-assessment, monitoring by commissioners and providers, and peer review visits. They describe what services should be aiming to provide and providers and commissioners should be moving towards meeting all applicable Quality Standards within the next two to five years. APPENDIX 3 lists the references sources on which the Quality Standards are based.

Through use of the Quality Standards we hope that:

1. The local community, service users and carers will know more about the services they can expect.
2. Commissioners will be supported in assessing and meeting the needs of their population, improving health and reducing health inequalities, and will have better service specifications.
3. Service providers and commissioners will work together to improve service quality.
4. Service providers and commissioners will have external assurance of the quality of local services.
5. Reviewers will learn from taking part in review visits.
6. Good practice will be shared.
7. Service providers and commissioners will have better information to give to the Care Quality Commission.

## Scope of the Quality Standards

Long-term ventilation is defined as "any child when medically stable requiring a mechanical aid for breathing after an acknowledged failure to wean [off the ventilator], or slow wean, three months after institution of ventilation" (Jardine et al, 1998). All ventilation was once exclusively undertaken in children's intensive care units. The vast majority of children who receive ventilation receive it in acute medical situations and, when this situation is resolved, the need for ventilation usually ceases. For a small group of children, however, the need for ventilation remains when the acute stage has passed. For this group of children, usually referred to as 'long-term ventilated children', the last two decades have seen a move from life in an intensive care unit to life at home. Ventilation is also now sometimes initiated electively in sleep units or ward environments. Within this group of children there are different levels of need, as defined in the National Framework for Children and Young People's Continuing Care (2010):

- High (Level 1): Is able to breathe unaided during the day but needs to go onto a ventilator for supportive ventilation. The ventilation can be discontinued for up to 24 hours without clinical harm.
- Severe (Level 2): 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.
- Priority (Level 3): This includes those with no respiratory drive at all who are dependent on ventilation at all times, including those with no respiratory drive when asleep or unconscious who require ventilation and one-to-one support while asleep as disconnection would be fatal.

These Standards apply to the care of children with an assessed and agreed continuing care package **and** those needing level 1 care who do not have a care package. They apply to both long-term invasive and non-invasive ventilation. A small number of Standards, or sections of Standards, apply only to children needing Level 2 or Level 3 care, or to children needing Level 1 ventilatory care but whose other conditions result in a higher complexity of need.

The Standards are about the care of children and young people. Planning for transition to adult services should start at around 14 years and transition normally takes place between the ages of 16 and 18. In exceptional circumstances transition may be delayed but should be completed by age 25. Flexibility in the age of transition may be necessary while commissioners and providers ensure appropriate arrangements are in place. Some services provide care for

adults as well as children and so transition will involve a change of funding arrangements at age 18 but may not require a change of care provider.

The Quality Standards for Services providing Long-Term Ventilation for Children and Young People should sit within organisations' overall clinical governance arrangements. The QRS Clinical Governance Quality Standards describe the clinical governance arrangements which should be in place. Compliance in NHS provider organisations will usually be assured through other regulatory bodies. Non-NHS organisations may wish to use the QRS Clinical Governance Quality Standards to assure themselves of the robustness of their overall clinical governance arrangements.

## Excel and PDF Versions

Using the Excel version of the Quality Standards has the following advantages:

- Standards applicable to different types of Service (XX-\*\*\*\*) can be selected more easily by using the 'Filter' function and selecting the appropriate service in Columns B to F. [delete if not required]
- The spreadsheet includes a 'CQC' tab. This updates automatically when a self-assessment is completed and allows services to see, and demonstrate, the extent to which they are achieving the CQC Key Lines of Enquiry.

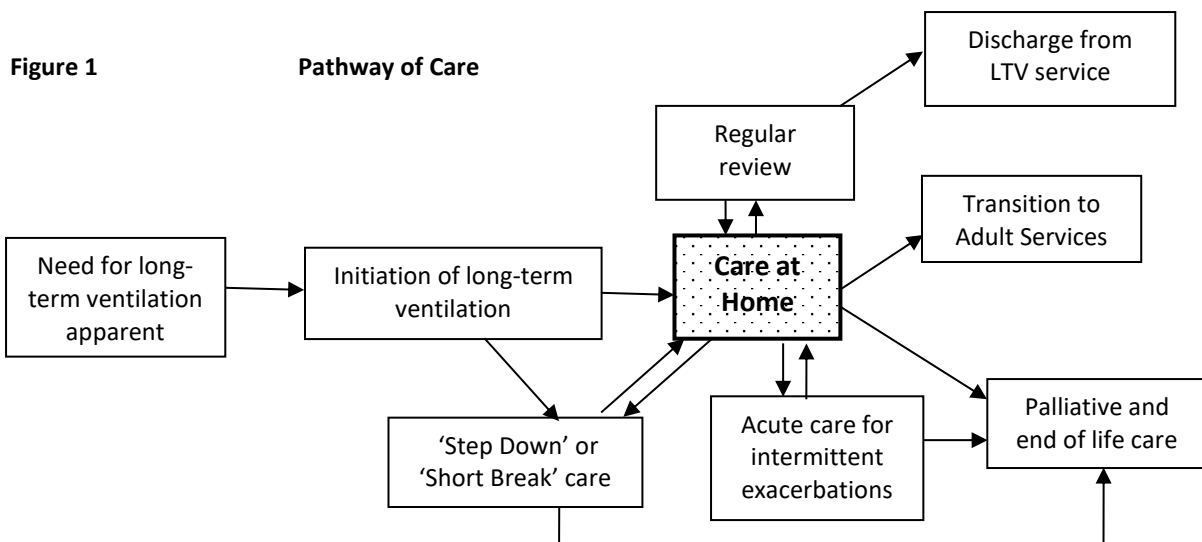
When using the Excel spreadsheet it is useful to know the following:

- If the tabs at the bottom of the spreadsheet do not appear, please minimise the spreadsheet and then maximise it again and the tabs should be there.
- 'Alt' and 'Enter' (together) allows you to put a new line within an Excel cell.

The PDF version includes appendices 1 to 5 which are not included in the Excel version.

## Pathway

The pathway of care for children and young people needing long-term ventilation is summarised in Figure 1.



Throughout this pathway, each child and young person needing long-term ventilation, and their families, should have the information, support and care that they need, in particular:

- A lead consultant from the Tertiary Long-Term Ventilation Service
- A nominated Community Children's Nurse who will liaise with local services as required and may also be the 'key worker'
- An agreed 'Personal Care Plan'
- A review of their care at least annually

Children needing Level 2 or 3 care, and some needing Level 1 ventilatory care who have other medical conditions, should also have:

- A nominated 'key worker'
- 24/7 access to children's nursing support who will be able to access medical advice if required

A range of services is needed to support the care of children and young people on long-term ventilation, including transport, education, housing, social care, ambulance and other services. These services are in addition to the wide range of local voluntary organisations, for example, Beavers and Brownies, who help to support social integration. A few children will be unable to return home and will become 'looked after children' needing long-term foster or residential care.

The specific services covered by these Quality Standards are:

- **Tertiary Long-Term Ventilation (LTV) Service**

This service will be based in a hospital providing paediatric specialist services, including a Paediatric Intensive Care Unit (PICU). Services initiating non-invasive ventilation only will be based in a hospital with a paediatric High Dependency Unit or PICU.

- **'Step Down / Short Break' Service**

This service will care for children and young people who do not need to be in hospital but who, for a variety of reasons, cannot be cared for at home. This will include times when families need a short break from providing care or could be 'transitional care' provided in a hospital environment. This service will provide care overnight as well as during the day. The environment and routines will be as similar to home as possible and the service will encourage links with the child's family, friends, school and other activities. The service may provide either 'step down' or 'short breaks' or both.

- **Home Support Service**

This service will support the ongoing care of the child or young person at home by providing a home care package. Home support may be provided by a range of different types of organisations including NHS Trusts, voluntary sector and private providers.

- **Acute Care Service**

Acute care during exacerbations may be provided at the hospital at which the Tertiary Children's LTV Service is based or may be provided by an acute hospital nearer the child's home. Children on long-term ventilation should be admitted only to hospitals with a Paediatric High Dependency or Intensive Care Unit meeting appropriate Quality Standards. Children on long-term ventilation may not need admission to high dependency or intensive care units but are likely to need the specialist respiratory and airway management competences of staff in these hospitals.

- **Children's Long-Term Ventilation Network**

All services will work together, and with commissioners, as part of a Children's Long-Term Ventilation Network. The area covered by a Network is not defined by these Quality Standards but will normally be the area served by one or a small number of Tertiary Children's LTV Service providers.

A single provider organisation may provide more than one of these services.

These Quality Standards do not cover paediatric critical care or palliative and end of life care for children in detail. Latest versions of the Quality Standards for these aspects of the pathway of care are available on the QRS website:

[www.qualityreviewservicewm.nhs.uk](http://www.qualityreviewservicewm.nhs.uk)

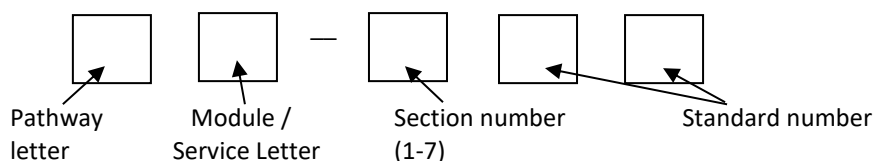
- Quality Standards: Care of Critically Ill and Critically Injured Children
- Quality Standards: Children and Young People's Palliative Care



## Structure of the Quality Standards

### QRS Quality Standards Reference Structure

QRS Quality Standard reference numbers have the following structure:



Each Standard is structured as follows:

<b>Reference Number (Ref)</b>	<p>This column contains the reference number for each Standard, which is unique to these Standards and is used for all cross-referencing. Each reference number is composed of two letters and three digits (see above and below for more detail).</p> <p>The reference column also includes a guide to how the Standard will be reviewed:</p> <table border="1" data-bbox="612 801 1214 1223"> <tr> <td>BI</td> <td>Background information</td> </tr> <tr> <td>Visit</td> <td>Visiting facilities</td> </tr> <tr> <td>MP&amp;S</td> <td>Meeting service users (children, young people, adults) and staff</td> </tr> <tr> <td>CNR</td> <td>Case note review or clinical observation</td> </tr> <tr style="background-color: #e0f0ff;"> <td>Doc</td> <td>Documentation should be available. Documentation may be written or be in the form of a website or other social media</td> </tr> </table> <p>The shaded area indicates the approach that will be used to reviewing the Quality Standard. APPENDIX 6 summarises the evidence needed for review visits.</p>	BI	Background information	Visit	Visiting facilities	MP&S	Meeting service users (children, young people, adults) and staff	CNR	Case note review or clinical observation	Doc	Documentation should be available. Documentation may be written or be in the form of a website or other social media
BI	Background information										
Visit	Visiting facilities										
MP&S	Meeting service users (children, young people, adults) and staff										
CNR	Case note review or clinical observation										
Doc	Documentation should be available. Documentation may be written or be in the form of a website or other social media										
<b>Quality Standard (QS)</b>	<p>This describes the quality that services are expected to provide.</p>										
<b>Notes</b>	<p><i>The notes give more detail about either the interpretation or the applicability of the Standard.</i></p>										

### Pathway and Service Letters:

The Standards are in the following sections:

PP-	Children and Young People Pathway	Long-Term Ventilation Service
PY-	Children and Young People Pathway	Children's Long-Term Ventilation Network
PZ-	Children and Young People Pathway	Commissioning

### Topic Sections:

Each section covers the following topics:

-100	Information and Support for Patients and Carers
-200	Staffing
-300	Support Services
-400	Facilities and Equipment

-500	Guidelines and Protocols
-600	Service Organisation and Liaison with Other Services
-700	Governance

'Information and Support for Children, Young People and Families' is the first section of the Standards because these aspects of their care should be clearly 'visible'. These Standards can also easily be reviewed by children, young people and families.

### Long-Term Ventilation Service Quality Standards (PP-\*\*\*)

The Long-Term Ventilation Service Quality Standards (QSs PP-\*\*\*) apply to all three types of long-term ventilation service:

- Tertiary Children's Long-Term Ventilation (LTV) Service
- 'Step Down / Short Break' Service
- Home Support Service

These Quality Standards (QSs) should be met by each service providing care for children and young people needing long-term ventilation. Where a service provides more than one type of long-term ventilation care (for example, home support and short breaks) they should meet all applicable Standards in each setting (but for peer review will only need to demonstrate compliance).

A small number of these Standards (QSs 0 to 0) should be met once for each child and not once in each service. Some Standards, or sections of Standards, apply only to Level 2 and Level 3 children and to children needing Level 1 ventilatory care but whose other conditions result in a higher complexity of need. This is shown adjacent to the heading of the Standard. **Where a section of a Quality Standard applies only to these children with more complex needs, this section is marked with an asterisk.**

These Standards are additional to the requirement to register with the Care Quality Commission as a provider of nursing and of personal care.

Most of the Quality Standards apply to all health services which provide long-term ventilation for children and young people although a few Standards are applicable only to one or two services:

QS Ref	Tertiary Children's LTV Service	'Step Down / Short Break' Service	Home Support Service
PP-107	N/A	N/A	√
PP-110	√	√	N/A
PP-202	√	N/A	N/A
PP-203	N/A	√	√
PP-205	N/A	√	√
PP-207	√	N/A	N/A
PP-301	N/A	√	√
PP-304	√	N/A	N/A
PP-501	√	N/A	N/A
PP-605	N/A	√	√

## Terminology

A glossary of terms and abbreviations used in the Quality Standards is given in Appendix 5. Certain terms are used throughout the Quality Standard:

<b>Term</b>	<b>Meaning</b>
Child	A child or young person needing long-term ventilation
Family	Parents, siblings, grandparents and other adults with responsibility for caring for the child or young person.
School	Nursery, school or college
Key Worker	The 'key worker'. This is described in more detail in Appendix 5.

### **Policies, Protocols, Guidelines and Procedures:**

The Quality Standards use 'policy', 'protocol', 'guideline' and 'procedure' based on the following definitions:

<b>Policy</b>	A course or general plan adopted by an organisation, which sets out the overall aims and objectives in a particular area.
<b>Protocol</b>	A document laying down in precise detail the tests or steps that must be performed.
<b>Guidelines</b>	Principles which are set down to help determine a course of action. They assist the practitioner to decide on a course of action but do not need to be automatically applied. Clinical guidelines do not replace professional judgement and discretion.
<b>Procedure</b>	A procedure is a method of conducting business or performing a task, which sets out a series of actions or steps to be taken.

For simplicity, some standards use the term 'guidelines and protocols' which should be taken as referring to policies, protocols, guidelines and procedures. All clinical guidelines should be based on national guidance, including NICE guidance where available. Local guidelines and protocols should specify the way in which national guidance will be implemented locally and should show consideration of local circumstances.

### **Comments on the Quality Standards**

The Quality Standards will be revised as new national guidance becomes available and as a result of experience of their use in peer review. Comments on the Quality Standards are welcomed and will be taken into account when they are updated. Comments should be sent to [qrs@nhs.net](mailto:qrs@nhs.net)

More information about QRS and its Quality Standards and reviews is available at [www.qualityreview servicewm.nhs.uk](http://www.qualityreview servicewm.nhs.uk) or 0121 612 2146.

## Services providing long-term ventilation for children and young people

Applicability: Services will need to select the Standards applicable to the type of service provided:	
All	All health services which provide long-term ventilation for children and young people
TLTV	Tertiary Children's LTV Services
SD/SB	'Step Down / Short Break' Services
HS	Home Support Services

Ref	Standard: Asterisked sections apply only to children needing level 2/3 care					
<b>Information and Support for Children, Young People and their Families</b>						
PP-101 All <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Service Information</b></p> <p>Each service should offer children, young people and families information covering:</p> <ol style="list-style-type: none"> <li>What the service provides</li> <li>Staff and facilities available</li> <li>How to contact the service for help and advice, including 'out of hours'</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>Information should be written in clear, plain English and should also be available in formats and languages appropriate to the needs of the local population. This should include developmentally appropriate information for children and young people, including those with learning disabilities. Information for children and young people should meet the <i>You're Welcome - Quality criteria for young people friendly health services London (DH, 2011)</i>.</li> </ol>
BI						
Visit						
MP&S						
CNR						
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PP-102 All <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Information about Long-Term Ventilation</b></p> <p>Children, young people and families should be offered discussion and access to written information about their long-term ventilation, including:</p> <ol style="list-style-type: none"> <li>Description of their condition and its impact</li> <li>Equipment including how to use it, preventing problems and what to do if they occur, maintenance and storage and how to return to equipment when no longer needed. This information may be in the form of a User Guide or Manual.</li> <li>Medication, including what it is for, when to take it, storage and possible side effects</li> <li>Management of acute and chronic changes in health</li> <li>Lifestyle advice, including nutrition, exercise and travel</li> <li>Housing and housing adaptations</li> <li>Emotional, spiritual and psychological support for children and young people themselves and for their families, including siblings</li> <li>Benefits advice, Personal Health Budgets and how to access charitable and voluntary sector resources</li> <li>Transport and mobility</li> <li>Other local services available for children and young people with complex care needs and how to access them</li> <li>Advance Care Planning (if appropriate)</li> <li>Relevant voluntary organisations and support groups</li> <li>Where to go for further information, including useful websites</li> </ol> <p><i>Notes:</i></p>
BI						
Visit						
MP&S						
CNR						
Doc						

	<ol style="list-style-type: none"> <li>1. As QS 0</li> <li>2. Information may not be relevant to all children and may be given only to children with particular needs or at different stages in the patient pathway. 'Access to information' means that <b>either</b> written information is given to the child, young person and family <b>or</b> they are given something in writing which 'sign-posts' them to information of appropriate quality.</li> <li>3. Information should be consistent with that given by other services within the Network. It may be helpful for services serving the same population to share the development and production of information for children, young people and families.</li> </ol>					
<p>PP-103</p> <p>All</p> <table border="1" style="width: 100%;"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Personalised Care Plan</b></p> <p>Each child and young person should have an agreed, up to date Personal Care Plan covering:</p> <ol style="list-style-type: none"> <li>a. Agreed outcomes</li> <li>b. Care provided by the young person and their family and any training needed</li> <li>c. Continuing care assessment or home care package*</li> <li>d. Therapeutic interventions (pharmacological and non-pharmacological)</li> <li>e. Equipment used and maintenance of equipment</li> <li>f. Contact details for their Home Support Service*</li> <li>g. How to access 24/7 Children's Nursing Support* (QS PP-205)</li> <li>h. Names and contact details for their: <ol style="list-style-type: none"> <li>i. 'Key worker'* (QS 0)</li> <li>ii. Community Children's Nurse (QS 0)</li> <li>iii. Tertiary Children's LTV Service consultant</li> <li>iv. Tertiary Children's consultant for any co-morbidities</li> <li>v. Community paediatrician</li> <li>vi. LTV Allied health professionals (QS PP-107)</li> </ol> </li> <li>i. Choices and options for short breaks*</li> <li>j. Religious, spiritual and cultural needs</li> <li>k. Transport arrangements and transport needs</li> <li>l. Emergency Health Care Plan (Escalation Plan) including the Acute Trust to which they will normally be admitted for acute exacerbations and information to be given to ambulance staff</li> <li>m. Risk assessment</li> <li>n. Planned review date and how to access a review more quickly, if necessary.</li> <li>o. Transition to adult services (if applicable)</li> <li>p. Weaning of ventilation (if applicable)</li> </ol> <p>This QS should be met once for each child (<b>not</b> once in each service) and should be communicated to the child's general practitioner.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>1. A nationally-recognised decision-support tool for care needs is given in the National Framework for Children and Young People's Continuing Care, DH 2010. No other nationally validated assessment tools are available at present.</li> <li>2. Other plans and checklists which should be in place are covered in QS PP-601 note 2.</li> <li>3. The 'key worker' and the nominated Community Children's Nurse may be the same person.</li> <li>4. The Emergency Health Care Plan may be called an Escalation or Exacerbation Plan. This may be part of the child's Care Plan or may be a separate document. The acute Trust to which the child is normally admitted should have a high dependency or intensive care unit.</li> </ol>
BI						
Visit						
MP&S						
CNR						
Doc						
<p>PP-104</p> <p>All</p> <table border="1" style="width: 100%;"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> </table>	BI	Visit	MP&S	<p><b>Formal Reviews of Care Plan and Continuing Care Assessment (if applicable)</b></p> <p>Each child should have a formal review of their care as required by their continuing care assessment (if applicable) and at least annually.</p>		
BI						
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<p>PP-105</p> <p>All</p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>'Key Worker' (Level 2/3 only)</b></p> <p>Each child should have a 'key worker' who they and their family can contact for queries, advice and support. This person should have responsibility for:</p> <ol style="list-style-type: none"> <li>Maintaining regular contact with the child and their family and providing information, support and advice covering all aspects of QSs 0</li> <li>Liaison with the child's named Community Children's Nurse (if a different person)</li> <li>Keeping relevant documentation up to date, including the Personal Care Plan, Agreement of Care, Education Health Care Plan and related risk assessments</li> <li>Identifying who is responsible for the management of equipment (QS PP-606) and associated consumables</li> <li>Informing other services involved with the child about changes to their condition or plan of care (QS 0)</li> <li>Informing the child's school of changes to their condition or plan of care (QS 0)</li> <li>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 (QS 0)</li> <li>Initiating and / or participating in multi-disciplinary discharge planning (QS PP-602)</li> <li>Initiating and updating the child's Common Assessment Framework (if applicable)</li> <li>Consideration of and acting on safeguarding issues</li> </ol> <p>This QS should be met once for each child (<b>not</b> once in each service).</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>Appendix 5 gives more detail of the role of the 'key worker'.</li> <li>Coordinating and maintaining an overview of the patient's care pathway is central to the key working function. The individual will not be expected to answer all queries and will 'signpost' or support patients and carers in accessing other services or advice. The 'key worker' may or may not be the main provider of health care. They should be available during office hours and cover for absences should be available. The 'key working' functions may be carried out by a small number of individuals rather than a single person, so long as there is good coordination between them.</li> <li>QS PP-601 covers arrangements for allocation of the 'key worker'.</li> <li>This QS is not applicable to children needing level 1 care only.</li> </ol>
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<p>PP-106</p> <p>All</p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Community Children’s Nurse</b></p> <p>Each child should have an identified Community Children’s Nurse with responsibility for liaison with community paediatricians and other local services, including education and housing services, to advocate for needs of the child and their family.</p> <p>This QS should be met once for each child (<b>not</b> once in each service).</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li><i>This may be the same person as the ‘key worker’ (QS 0) or may be different.</i></li> <li><i>Tertiary Children’s LTV Services should ensure a Community Children’s Nurse is identified as soon as the need for long-term ventilation becomes apparent.</i></li> </ol>
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<p>PP-107</p> <p>HS</p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Agreement of Care (Level 2/3 only)</b></p> <p>An ‘Agreement of Care’ between the family and the Home Support Service provider should be negotiated and agreed covering the family and service’s responsibilities and arrangements for staff while working within the family home.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li><i>The ‘Agreement of Care’ may have other names, such as the ‘Family Service Agreement’.</i></li> <li><i>This QS is applicable only to Home Support Services.</i></li> </ol>
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<p>PP-108</p> <p>All</p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Education Health Care Plan</b></p> <p>Each child should have an Education Health Care Plan covering at least:</p> <ol style="list-style-type: none"> <li>School attended</li> <li>Transport to and from school*</li> <li>Care required whilst at school*</li> <li>Responsibilities of carers and of school staff</li> <li>Training and competency requirements for whoever is providing the child’s care in school*</li> <li>Likely problems and what to do if these occur</li> <li>What to do in an emergency (or a copy of the child’s Emergency Health Care Plan)</li> <li>Arrangements for liaison with the school</li> <li>Review date and review arrangements</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li><i>For children needing level 1 care this QS may only apply to overnight stays.</i></li> </ol>
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<p>PP-109</p> <p>All</p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Self-Care and Family Involvement in Care</b></p> <p>Children and young people themselves, and family members, should have information, encouragement, support and training to enable them fully to participate in their care. Training and evidence of completion of competences should be recorded in the child’s case notes, reviewed at least annually and updated as necessary.</p>
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<p>PP-110</p> <p>TLTV SD/SB</p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Facilities for Families</b></p> <p>Services providing overnight care away from the child’s home should have:</p> <ol style="list-style-type: none"> <li>Information for families on service routines, facilities that families may want to use, transport facilities and car parking</li> <li>Appropriate facilities for families, including for other children</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li><i>This QS is not applicable to Home Support Services.</i></li> <li><i>Appropriate facilities for families should normally include:</i> <ul style="list-style-type: none"> <li><i>A comfortable chair at the child’s bedside, somewhere comfortable to sit away from the ward or child’s bedroom and a quiet room for relatives</i></li> <li><i>A toilet and washing area and a kitchen or other facility for getting hot food</i></li> <li><i>Changing and play areas for other young children</i></li> </ul> </li> </ol>
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	<ul style="list-style-type: none"> <li>• <i>Overnight facilities including a foldaway bed or pull-out chair-bed next to the child and, ideally, accommodation on site but away from the ward or child's bedroom</i></li> <li>• <i>'Personal care packs' for relatives who unexpectedly stay overnight</i></li> <li>• <i>Facilities for children with severe physical disability, including hoists and bath/shower equipment</i></li> </ul>					
<p>PP-111</p> <p>All</p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Play Support</b></p> <p>Children and young people and their families should have direct access to:</p> <ol style="list-style-type: none"> <li>a. Play support to enable the child's development and well-being</li> <li>b. Play and distraction during any painful or invasive procedures</li> </ol> <p>Notes:</p> <ol style="list-style-type: none"> <li>1. <i>Qs PP-202 and PP-203 give detail of the staffing and competences expected in each service.</i></li> </ol>
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<p>PP-112</p> <p>All</p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Support for Families</b></p> <p>Children and young people and their families should have direct access to:</p> <ol style="list-style-type: none"> <li>a. Psychological support for the child, parents, siblings and other close family members</li> <li>b. An assessment of the needs of family carers</li> <li>c. Information and advice on services available to provide support to siblings and family members</li> </ol> <p>Notes:</p> <ol style="list-style-type: none"> <li>1. <i>Qs PP-202 and PP-203 give detail of the staffing and competences expected in each service.</i></li> <li>2. <i>Bereavement support is covered in the Quality Standards for Services providing Palliative Care for Children and Young People.</i></li> <li>3. <i>Assessment of the needs of family carers should be part of the continuing care assessment (when applicable) and may be through referral to social care.</i></li> <li>4. <i>A range of psychological support should be available including counselling and clinical psychology support.</i></li> </ol>
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<p>PP-196</p> <p>All</p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>General Support for Children and their Families</b></p> <p>Each child and their family should have easy access to the following services. Information about these services should be easily available:</p> <ol style="list-style-type: none"> <li>a. Interpreter services</li> <li>b. PALS and how to make a comment, compliment or complaint</li> <li>c. Spiritual support</li> <li>d. HealthWatch or equivalent organisation</li> </ol> <p>Notes:</p> <ol style="list-style-type: none"> <li>1. <i>Information should be written in clear, plain English and should also be available in formats and languages appropriate to the needs of the local population. This should include developmentally appropriate information for children and young people, including those with learning disabilities. Information for children and young people should meet the 'You're Welcome - Quality criteria for young people friendly health services London (DH, 2011).).</i></li> <li>2. <i>This QS is about 'signposting' to relevant services. The actual services available may be different in different areas.</i></li> </ol>
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<p>PP-199</p> <p>All</p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Involving Children, Young People and Families</b></p> <p>The service should have:</p> <ol style="list-style-type: none"> <li>a. Mechanisms for receiving feedback from children, young people and their families about the treatment and care they receive</li> <li>b. Mechanisms for involving children, young people and families in decisions about the organisation of the service</li> <li>c. Examples of changes made as a result of feedback and involvement of children, young people and their families</li> </ol>
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	<p><i>Notes</i></p> <p>1. <i>The arrangements for receiving feedback from children, young people and families may involve surveys, including the national patient survey, focus groups and/or other arrangements. They may involve Trust-wide arrangements so long as issues relating to the specific service can be identified.</i></p>
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## Staffing

<p>PP-201</p> <p>All</p> <table border="1" style="width: 100%;"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Clinical Leadership</b></p> <p>The service should have the following nominated clinical leads:</p> <ol style="list-style-type: none"> <li>a. Lead nurse or other registered healthcare professional with:             <ol style="list-style-type: none"> <li>i. Training and experience in the care of children on long-term ventilation</li> <li>ii. Competences in management and leadership</li> </ol> </li> <li>b. Lead paediatric respiratory or intensive care consultant (Tertiary Children’s LTV Services only)</li> </ol> <p>Clinical leads should have some job-planned time allocated for their leadership role within the service, including for ensuring all relevant Quality Standards are met.</p> <p><i>Notes:</i></p> <p>1. <i>Tertiary Children’s LTV Services should meet both ‘a’ and ‘b’.</i></p>
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<p>PP-202</p> <p>TLTV</p> <table border="1" style="width: 100%;"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Staffing Levels – Tertiary Children’s LTV Services</b></p> <p>The service should have sufficient staff with appropriate competences for the usual number of children cared for by the service, their dependency and the complexity of their needs. Staffing should include:</p> <ol style="list-style-type: none"> <li>a. Medical staff</li> <li>b. Nursing staff with a minimum of 75% children’s trained nurses Children’s carers, all of whom should have a Regulated Qualifications Framework (RQF) level 3 qualification in a child or young adult-related subject (or equivalent)</li> <li>c. Physiotherapy (Monday to Friday and on call at weekends)</li> <li>d. Occupational therapy (Monday to Friday)</li> <li>e. Dietetics (Monday to Friday)</li> <li>f. Speech and language therapy (Monday to Friday)</li> <li>g. Clinical psychological support (Monday to Friday)</li> <li>h. Play support (Daily)</li> <li>i. Youth workers (Flexible availability depending on the needs of the child)</li> </ol> <p>Staffing should be sufficient to provide 24/7 advice across the network (QS PP-207). Cover for absences should be available so that the functions of the service can continue during times of annual leave, study leave and short-term sickness.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>1. <i>Staffing may include volunteers with appropriate competences or others paid from personal budgets.</i></li> <li>2. <i>Staffing should be sufficient to meet Quality Standards relating to the ‘key working function’ (QS 0) and nominated Community Children’s Nurse (QS 0) unless these are provided by another service.</i></li> <li>3. <i>A minimum of 80% children’s trained nurses is desirable and services should be working towards this level.</i></li> <li>4. <i>This QS applies only to Tertiary Children’s LTV Services. Staff should be available in all settings where the service is provided, for example, during admission and for out-patient clinics.</i></li> </ol>
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### Staffing Levels – Home Support and ‘Step Down / Short Break’ Services

The service should have sufficient staff with appropriate competences for the usual number of children cared for by the service, their dependency and the complexity of their needs. Staffing should include:

- a. Registered nursing staff, of whom a minimum should be 75% children’s trained nurses
- b. Children’s carers, all of whom should have a RQF level 3 qualification in a child or young adult-related subject (or equivalent)
- c. Physiotherapy (Monday to Friday and on call at weekends)
- d. Occupational therapy (Monday to Friday)
- e. Speech and language therapy (Monday to Friday)

Staffing should be sufficient to meet Quality Standards relating to Observation of Practice (QS PP-206) and Weekly Review (QS PP-604). Staffing should be sufficient to meet Quality Standards relating to the ‘key worker’\* (QS 0), nominated Community Children’s Nurse (QS 0) and 24/7 Children’s Nursing Support\* (QS PP-205) unless these are separately commissioned. Cover for absences should be available so that the functions of the service can continue during times of annual leave, study leave and short-term sickness.

#### Notes:

1. Staffing may include volunteers with appropriate competences or others paid from personal budgets.
2. Allied health professional and other support services are covered in QS PP-301.
3. If the service also provides care for adults then 75% of nursing staff caring for children and young people should be children’s trained nurses.
4. A minimum of 80% of registered nurses being children’s trained nurses is desirable and services should be working towards this level.
5. Allied health professionals should have sessional time allocated for their work with the Long-Term Ventilation Service (but may not be full-time posts).
6. Cover for absences may be achieved through agreed arrangements with another service.
7. This QS is not applicable to Tertiary Children’s LTV Services.

<p>PP-204</p> <p>All</p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Competence Framework and Training Plan</b></p> <p>Anyone with caring responsibilities for children and young people on long-term ventilation (QS PP-202) should have, and should maintain, competences appropriate to their role in, at least:</p> <ol style="list-style-type: none"> <li>Ventilation</li> <li>Resuscitation</li> <li>Transporting ventilated children *</li> <li>Professional boundaries</li> <li>Child safeguarding</li> <li>Working in the home environment* (where applicable)</li> <li>Infection control and disposal of clinical waste</li> <li>Use of relevant medical devices</li> </ol> <p>Where appropriate for the needs of the child:</p> <ol style="list-style-type: none"> <li>Tracheostomy care*</li> <li>Oxygen administration</li> <li>Humidification*</li> <li>Nebulisation</li> <li>Saturation monitoring</li> <li>Transcutaneous carbon dioxide monitoring*</li> <li>Urinary catheterisation*</li> <li>Spinal care*</li> <li>Enteral feeding*</li> <li>Postural care</li> <li>Respiratory physiotherapy management including use of equipment</li> <li>Neuro-physiotherapy management including techniques and use of equipment (if required)</li> <li>Speaking valve placement*</li> </ol> <p>A competence framework should show the competences expected for different roles within the service and how competences will be assessed. A training plan should cover achievement and maintenance of these competences.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li><i>This QS applies to all staff identified in QS PP-202 or PP-203 except doctors in training where expected competences are laid down by the relevant Royal College. The Coventry and Warwickshire Children and Young People’s Interactive Competency Framework may be helpful in achieving this QS and can be found at <a href="http://www.covandwarkschildcomps.org.uk">www.covandwarkschildcomps.org.uk</a>. Further guidance on competences needed is available from the Royal College of Nursing or Skills for Health <a href="http://www.skillsforhealth.org.uk">www.skillsforhealth.org.uk</a></i></li> <li><i>This QS is additional to the competences of everyone working with children, such as infection control, information governance, moving and handling, Control of Substances Hazardous to Health and caring for children with disabilities.</i></li> <li><i>Where volunteers and or others paid from personal budgets are part of the core staffing (QS PP-202 or PP-203), the competences they are expected to achieve should also be specified.</i></li> </ol>
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<p>PP-205</p> <p>SD/SB HS</p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>24/7 Children’s Nursing Support (Level 2/3 only)</b></p> <p>A registered children’s nurse with competences in the care of children needing long-term ventilation should be available at all times (24/7). This nurse should:</p> <ol style="list-style-type: none"> <li>Have access to each child’s latest Personal Care Plan (QS 0) and other relevant assessments and plans</li> <li>Have information about the equipment used and maintenance arrangements</li> <li>Have access to the child’s Tertiary Children’s LTV Service for advice (QS PP-207)</li> </ol> <p>24/7 Children’s Nursing Support should be organised to give reasonable continuity of care. Staff providing this service should have direct contact with the family at least quarterly either through providing direct care or through observation of practice of staff providing care (QS PP-206).</p>
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	<p><b>Notes:</b></p> <ol style="list-style-type: none"> <li>24/7 Children's Nursing Support may be provided by the service itself or may be separately commissioned (QS PZ-603). This QS may be achieved through collaboration with other services.</li> <li>The 24/7 Children's Nursing Support will also require contact numbers for staff, contact numbers for all families, current ventilation prescriptions and Emergency Health Care Plans, current competences for each carer for each child, adverse weather policy.</li> <li>More detail of other relevant assessments and plans is given in QS PP-601.</li> <li>This QS does not apply to Tertiary Children's LTV Services.</li> </ol>					
<p>PP-206</p> <p>All</p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Observation of Practice</b></p> <p>All children's carers should have their practice observed by a registered healthcare professional with competences in the care of children needing long-term ventilation for at least one hour every two months. Observation of practice should normally take place in the setting where care is delivered.</p> <p><b>Notes:</b></p> <ol style="list-style-type: none"> <li>The purpose of observation of practice is to ensure staff providing care are maintaining appropriate competences and behaviour, and are abiding by the service's guidelines, policies and procedures. The carers' employing organisation is responsible for ensuring action is taken to address any issues identified during observation of practice.</li> </ol>
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<p>PP-207</p> <p>TLTV</p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Tertiary LTV Advice Service</b></p> <p>The following staff should be available at all times (24/7) to provide advice to services with the network:</p> <ol style="list-style-type: none"> <li>Paediatric respiratory or intensive care consultant</li> <li>Registered children's nurse with competences in the care of children needing long-term ventilation</li> </ol> <p><b>Notes:</b></p> <ol style="list-style-type: none"> <li>This QS applies only to Tertiary Children's LTV Services.</li> </ol>
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<p>PP-208</p> <p>All</p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Emotional Support for Staff</b></p> <p>All staff should have direct access to emotional and psychological support or counselling.</p> <p><b>Notes:</b></p> <ol style="list-style-type: none"> <li>This QS also applies to administrative and clerical staff (QS PP-299).</li> <li>Access to psychological support through occupational health services should be available but is not sufficient for compliance with this QS.</li> <li>This QS should also apply to staff employed through Personal Health Care Budgets.</li> </ol>
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<p>PP-209</p> <p>All</p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Clinical Supervision</b></p> <p>All healthcare professionals should be offered regular clinical supervision appropriate to their role at least quarterly. This should include 'safeguarding supervision'.</p>
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<p>PP-299</p> <p>All</p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Administrative and Clerical Support</b></p> <p>Administrative, clerical and data collection support should be appropriate for the number of children cared for by the service.</p> <p><b>Notes:</b></p> <ol style="list-style-type: none"> <li>The amount of administrative, clerical and data collection support is not defined. Clinical staff should not, however, be spending unreasonable amounts of time which could be used for clinical work on administrative tasks and data entry.</li> </ol>
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<p><b>Support Services</b></p>						

<p>PP-301 SD/SB HS</p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Support Services – Home Support and ‘Step Down / Short Break’ Services</b></p> <p>The following services should be available to support children on long-term ventilation in the location where care is delivered:</p> <ol style="list-style-type: none"> <li>Dietetics (Monday to Friday)</li> <li>Clinical psychological support (Monday to Friday)</li> <li>Play support (Daily)</li> <li>Youth workers (Flexible availability depending on the needs of the child)</li> <li>LTV Allied Health Professionals (Monday to Friday)</li> </ol> <p>Cover for absences should be available so that the services can continue during times of annual leave, study leave and short-term sickness.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li><i>‘Daily’ means seven days a week.</i></li> <li><i>If support services are part of the ‘core team’ (QS PP-203) then that particular aspect of this QS is not applicable.</i></li> <li><i>This QS is not applicable to Tertiary Children’s LTV Services.</i></li> </ol>
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<p>PP-302 All</p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Other Services Providing Support Where Care is Delivered</b></p> <p>The following services should be available to support children on long-term ventilation in the location where care is delivered:</p> <ol style="list-style-type: none"> <li>Education services including educational psychology (Monday to Friday)</li> <li>Chaplain or multi-faith representative (24/7)</li> <li>Home Oxygen Assessment and Review Service (7/7)</li> <li>Transport services for children with complex needs* (Monday to Friday)</li> <li>Social work (Monday to Friday) and Emergency Duty Team</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li><i>‘Daily’ means seven days a week.</i></li> <li><i>If support services are part of the ‘core team’ (QS PP-202 or PP-203) then that particular aspect of this QS is not applicable.</i></li> </ol>
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<p>PP-303 All</p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Other Support Services</b></p> <p>Timely access to the following services should be available:</p> <ol style="list-style-type: none"> <li>Pharmacy advice (telephone advice 7/7)</li> <li>Respiratory physiology, lung function tests and sleep studies</li> <li>Wheelchair and / or seating assessment, supply and maintenance service (if required)</li> <li>Assessments for housing adaptations*</li> <li>Community paediatrician</li> <li>Continence services (if required)</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li><i>‘Timely’ is not strictly defined but should include arrangements for urgent access as well as routine referrals.</i></li> </ol>
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<p>PP-304 TLTV</p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Support Services – Tertiary Children’s LTV Services</b></p> <p>Tertiary long-term ventilation services should be based on the same hospital site as:</p> <ol style="list-style-type: none"> <li>Paediatric Intensive Care Unit (if initiating invasive ventilation) or Paediatric High Dependency Unit (If initiating non-invasive ventilation only). These services should meet applicable Paediatric Intensive Care Society Standards for the Care of Critically Ill Children 5th Edition (2015)</li> <li>Consultant-led ENT service</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li><i>This QS applies to Tertiary Children’s LTV Services only.</i></li> </ol>
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## Facilities and Equipment

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### Equipment

Timely access to the following equipment should be available:

#### Each child who is ventilator dependent (level 2 or 3):

- a. Two ventilators including internal and external battery backup
- b. Two oxygen saturation monitors **or** one oxygen saturation monitor and robust arrangements for replacement within 12 hours
- c. Hand-held saturation monitor
- d. Two sets of suction equipment
- e. Access to a mobile phone and to a land line in the home (or back up mobile)
- f. Back up lighting
- g. Adequate number of electrical points
- h. Supply of consumables
- i. Appropriate storage for equipment and consumables
- j. If required:
  - i. Two sets of appropriate humidification equipment
  - ii. Tracheostomy care equipment
  - iii. Manual resuscitation bag
  - iv. Height adjustable (profiling) bed / cot
  - v. Manual handling equipment
  - vi. 24-hour postural management equipment; including a wheelchair suitable for safe transportation of the child and young person and their equipment. Specialist seating as assessed for the child / young person if different to the wheelchair
  - vii. Augmentative and alternative communication aids
  - viii. Speaking valve placement
  - ix. Feed pump
  - x. Nebuliser
  - xi. Carbon dioxide monitoring equipment
  - xii. Chest physiotherapy equipment

#### Each child needing level 1 ventilatory support:

- k. One ventilator in the home
- l. Access to a replacement ventilator within 24 hours

#### Where a care package is in place then the following should be available for staff working in the home:

- m. Call system
- n. Adequate seating for care staff
- o. Adequate lighting, ideally dimmable background lighting

All equipment should be fully maintained and serviced with appropriate arrangements for emergency replacement in the event of equipment failure and access to technical support within 24 hours for equipment care (QS PP-606). All equipment should be supported by training and manuals.

#### Notes:

1. QS PP-606 covers responsibilities for equipment and consumables.
2. 'Timely' is not strictly defined but should ensure that there is no delay in the availability of equipment when needed for the care of a child.

## Guidelines and Protocols

<p>PP-501 TLTV</p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Guidelines on Initiation of Ventilation</b></p> <p>Guidelines on initiation of ventilation should be in use covering at least:</p> <ol style="list-style-type: none"> <li>Involvement of the family and consent for initiation of long-term ventilation</li> <li>Multi-disciplinary discussion involving staff of the Tertiary Children’s LTV Service*</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li><i>This QS applies only to Tertiary Children’s LTV Services.</i></li> </ol>
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<p>PP-502 All</p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Clinical Guidelines</b></p> <p>Clinical guidelines should be in use covering common problems in the care of children on long-term ventilation, including:</p> <ol style="list-style-type: none"> <li>Pressure sores and tissue viability</li> <li>Tracheostomy care*</li> <li>Ventilation</li> <li>Suction of natural and artificial airways*</li> <li>Oxygen therapy</li> <li>Saturation monitoring</li> <li>Transcutaneous carbon dioxide monitoring (if required)</li> <li>Resuscitation</li> <li>Enteral feeding *</li> <li>Venous thrombo-embolism assessment and prevention*</li> <li>Medication (if required)</li> <li>Chest management</li> <li>Postural care</li> <li>Manual handling</li> <li>Speaking valve*</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li><i>Clinical guidelines should describe the general approach or policy of the service. Details of the care of individual children will be given in their Personal Care Plan (QS 0).</i></li> </ol>
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<h2>Service Organisation and Liaison with Other Services</h2>						
<p>PP-601 All</p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Service Organisation</b></p> <p>The service should have an operational procedure covering, at least:</p> <ol style="list-style-type: none"> <li>Criteria and arrangements for referral into the service</li> <li>Handover to and from 24/7 Children’s Nursing Support (QS PP-205) and ensuring all appropriate information is available</li> <li>Documentation of Personal Care Plan and Care Package in the Personal Care Record (QS 0)</li> <li>Agreement and documentation of all relevant assessments and plans (note 3)</li> <li>Confirmation of the child’s:             <ol style="list-style-type: none"> <li>‘Key worker’* (QS 0)</li> <li>Community Children’s Nurse (QS 0)</li> <li>Tertiary Children’s LTV Service consultant</li> <li>Community paediatrician</li> <li>Allied healthcare professionals</li> </ol> </li> <li>Communication of any changes to the plan of care to the:             <ol style="list-style-type: none"> <li>Local acute Trust to which the child is usually admitted for acute exacerbations</li> <li>Child’s school and, if necessary, changing their Education Health Care Plan</li> </ol> </li> </ol>
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	<p>g. Consideration of and acting on, safeguarding issues</p> <p>h. Indications and arrangements for accessing the Tertiary LTV Advice Service (QS PY-604)</p> <p>i. Arrangements for professional carers to work in other settings, such as the 'Step Down' service or local acute hospital*:</p> <p>i. For training</p> <p>ii. To provide care for the child during a short break or hospital stay</p> <p>j. System for support for staff (QS PP-208)</p> <p>k. Discharge to the care of 'universal' children's services or specialist disability services</p> <p>l. Criteria and arrangements for referral to children's palliative care services</p> <p>m. Governance arrangements for providing consultations, assessments and therapeutic interventions, virtually, in the home or in informal locations.</p> <p><b>Notes:</b></p> <ol style="list-style-type: none"> <li>1. <i>Criteria and arrangements for referral into and discharge from the service should be consistent with those commissioned (QS PZ-603).</i></li> <li>2. <i>Relevant assessments and plans may include: Children's Continuing Care Assessment* (if applicable), Agreed Care Package*, Agreement of Care*, Personal Care Plan, Emergency Health Care (Escalation) Plan, Ventilation Care Plan, Tracheostomy Care Plan* (if applicable), Chest Management Plan (if applicable), Risk Assessment, Power Failure Plan, Equipment Failure Plan, 'Going Out' Plan, including care of equipment*, Overnight Checklists*, Stock Checklists* and Advanced Care Plan (if applicable).</i></li> <li>3. <i>The following may be part of the Operational Procedure or may be separate:</i> <ol style="list-style-type: none"> <li>i. <i>Multi-Agency Care Planning (QS PP-603)</i></li> <li>ii. <i>Discharge from Hospital (QS PP-602)</i></li> <li>iii. <i>Transition (QS PP-608)</i></li> </ol> </li> <li>4. <i>The Emergency Health Care Plan may also be called an Escalation or Exacerbation Plan. This may be part of the child's Care Plan or may be a separate document. The acute Trust to which the child is normally admitted should have a high dependency or intensive care unit. Acute Trusts to which children on long-term ventilation are admitted with acute exacerbations are admitted should have a high dependency or intensive care unit.</i></li> </ol>					
<p>PP-602</p> <p>All</p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Discharge Guidelines</b></p> <p>Network-agreed guidelines for discharge from hospital (QS PY-602) should be in use.</p> <p><b>Notes:</b></p> <ol style="list-style-type: none"> <li>1. <i>QS PY-602 Note 4 gives more detail of available guidance on discharge from hospital.</i></li> </ol>
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<p>PP-603</p> <p>All</p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Multi-Agency Care Planning Policy</b></p> <p>A policy covering multi-agency care planning and continuing care assessment should be in use covering all aspects of QS 0 and involving:</p> <ol style="list-style-type: none"> <li>a. The child themselves and their family</li> <li>b. The child's general practitioner</li> <li>c. The child's 'key worker'*, community children's nurse, Tertiary Children's LTV Service consultant, allied healthcare professionals, community paediatrician and home care provider</li> <li>d. Social work, education and relevant voluntary service representatives</li> </ol> <p>Links with Children's Assessment Framework processes and the 'Team around the Child' should be clear.</p> <p><b>Notes:</b></p> <ol style="list-style-type: none"> <li>1. <i>These arrangements may be part of the Operational Procedure (QS PP-601) or may be separate.</i></li> <li>2. <i>This policy should be consistent with the 'National Framework for Children and Young People's Continuing Care' (2010) and the NHS Commissioning Board 'Service Specification E7c 'Paediatric Long-Term Ventilation'.</i></li> </ol>
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<p>PP-605</p> <p>SD/SB HS</p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Guidelines on Communication with Ambulance Service</b></p> <p>The ambulance service should be informed of:</p> <ol style="list-style-type: none"> <li>a. All children needing long-term ventilation at home and any special arrangements, including transport of staff and equipment, and the acute Trust to which they should normally be admitted for acute exacerbations</li> <li>b. When the child of young person is no longer at a residential address.</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>1. The ambulance service does not need to be informed of short-term absences from the child's usual address, for example, for respite care or hospital admission.</li> <li>2. Acute Trusts to which children on long-term ventilation are admitted with acute exacerbations are admitted should have a high dependency or intensive care unit.</li> <li>3. This QS is not applicable if the local ambulance service does not accept this information. It is also not applicable to Tertiary Children's LTV Services.</li> <li>4. Information held by the family about emergency ambulance transport is covered in QS 0.</li> </ol>
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<p>PP-606</p> <p>All</p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Equipment Policy</b></p> <p>An Equipment Policy should be in use covering responsibilities and arrangements for:</p> <ol style="list-style-type: none"> <li>a. Setting up equipment</li> <li>b. Maintenance and servicing of equipment</li> <li>c. Ordering and supply of consumables</li> <li>d. Emergency replacements</li> <li>e. Replacement of breakages</li> <li>f. Emergency contact details</li> <li>g. Return of equipment when no longer needed</li> </ol>
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<p>PP-607</p> <p>All</p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Equipment Responsibilities</b></p> <p>The service should maintain a register of equipment, maintenance and servicing arrangements for each child. This register should be available to 24/7 Children's Nursing Support (QS PP-205) and Tertiary LTV Advice Service (QS PP-207).</p>
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<p>PP-608</p> <p>All</p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Transition Guidelines</b></p> <p>Guidelines on transition should be in use, covering:</p> <ol style="list-style-type: none"> <li>a. Age guidelines for timing of transition</li> <li>b. Involvement of the young person and their family in the decision about transition</li> <li>c. Multi-disciplinary planning of the transition with primary health care, social care, education service and adult services</li> <li>d. Joint meetings with the young person, their family and children's and adult services prior to transition</li> <li>e. Responsibility for key working functions during the transition period</li> <li>f. A preparation period and education programme relating to transition</li> </ol>
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	<p>g. Arrangements for monitoring during the time immediately after transition</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>1. Transition may be from neonatal to children's services or from children's to adult services. The same principles will apply to other 'handovers' of care. Guidelines on transition to adult services should comply with national guidance on continuing care for children and adults including age guidelines: notification at 14, joint assessment at 16, agreement in principle at 17 and transition at 18. In exceptional circumstances transition may be delayed but should be completed by age 25.</li> </ol>					
<p>PP-609</p> <p>All</p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Liaison with Support Services</b></p> <p>Meetings should be held at least annually to review arrangements for liaison and address any problems identified with:</p> <ol style="list-style-type: none"> <li>a. Special Educational Needs services</li> <li>b. Transport services*</li> <li>c. Equipment supply and maintenance services</li> <li>d. Acute Trusts to which children are normally admitted with acute exacerbations (if not the Tertiary Children's LTV Service)</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>1. This QS is additional to day-to-day liaison arrangements and should involve staff with management responsibility for the service. This QS does not require a face to face meeting - a planned telephone or video-conference is sufficient for compliance with this QS.</li> </ol>
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<p>PP-610</p> <p>All</p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Children's Long-Term Ventilation Network</b></p> <p>The service should have representation on the Children's Long-Term Ventilation Network and regularly receive information about the work of the Network.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>1. The area covered by a Network is not defined by these Quality Standards but will normally be the area served by one or a small number of Tertiary Children's LTV Service providers.</li> </ol>
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<h2 style="color: #00A651;">Governance</h2>						
<p>PP-701</p> <p>All</p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Data Collection</b></p> <p>There should be regular collection of data and monitoring of:</p> <ol style="list-style-type: none"> <li>a. Number of children cared for by the service</li> <li>b. Number of staff involved in each care package*</li> <li>c. Percentage of shifts not covered* (excluding shifts cancelled by parents or due to admission of children to hospital)</li> <li>d. Proportion of face to face contact time provided by registered health care professionals*</li> <li>e. Achievement of weekly review visits* (QS PP-604)</li> <li>f. Frequency of observation of practice for all children's carers* (QS PP-206)</li> <li>g. Calls to the 24/7 Children's Nursing Support (QS PP-205) outside normal working hours*</li> <li>h. Achievement of expected timescales for discharge (QS PY-602)</li> <li>i. Reporting of required data to the Central LTV Pathway Team*</li> <li>j. Other key performance indicators agreed by the National Service Specification* or Children's Long-Term Ventilation Network</li> </ol> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>1. 'c', 'e' and 'g' are not applicable to Tertiary Children's LTV Services.</li> <li>2. The Royal Brompton Hospital 'Hospital to Home' software may be helpful in collecting these data - <a href="http://nww.hospitaltohome.rbht.nhs.uk">http://nww.hospitaltohome.rbht.nhs.uk</a></li> </ol>
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<p>PP-798</p> <p>All</p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Review and Learning</b></p> <p>The service should have appropriate multi-disciplinary arrangements for review of, and implementing learning from, positive feedback, complaints, outcomes, incidents and ‘near misses’.</p>
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<p>PP-799</p> <p>All</p> <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Document Control</b></p> <p>All policies, procedures and guidelines should comply with Trust or employing organisation’s document control procedures.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li>Specific documentary evidence of compliance is not required. This QS will be determined from the other documentary information provided.</li> <li>Copies of the organisations document control policies are also required for compliance with this QS</li> </ol>
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## Childrens Long-term ventilation Network

The Quality Standards expect that all services will work together, and with commissioners, as part of a Children's Long-Term Ventilation Network. The area covered by a Network is not defined by these Quality Standards but will normally be the area served by one or a small number of Tertiary Children's LTV Service providers.

Ref	Standard: Asterisked sections apply only to children needing level 2/3 care					
<b>Information and Support for Children, Young People and their Families</b>						
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PY-199 <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<b>Involving Children and Families</b> The network should have mechanisms for: <ol style="list-style-type: none"> <li>Receiving feedback from children and families about the treatment and care they receive across patient pathways</li> <li>Involving children and families in decisions about the organisation of the network</li> </ol>
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<b>Staffing</b>						
PY-201 <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<b>Network Lead Clinician</b> The network should have an identified Lead Clinician with time identified in their job plan for their work in the network. The Lead Clinician should be actively involved in providing services for children needing long-term ventilation.
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PY-203 <table border="1"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<b>Network Competences</b> The Network should have agreed a framework of the competences expected for staff providing care for children needing long-term ventilation. <i>Notes:</i> <ol style="list-style-type: none"> <li>The Coventry and Warwickshire Children and Young People's Interactive Competency Framework is an example of an appropriate framework and can be found at <a href="http://www.covandwarkschildcomps.org.uk">www.covandwarkschildcomps.org.uk</a>. Further guidance on competences needed is available from the Royal College of Nursing or Skills for Health <a href="http://www.skillsforhealth.org.uk">www.skillsforhealth.org.uk</a></li> </ol>
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PY-204 <table border="1" data-bbox="204 293 284 434"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Network Wide Training and CPD</b></p> <p>The network should provide a range of opportunities for:</p> <ol style="list-style-type: none"> <li>Staff from services within the network to achieve the expected competences (QS PY-203)</li> <li>Continuing Professional Development and refresher training to help staff maintain expected competences</li> </ol> <p>The opportunities available should involve periods of supernumerary clinical practice in other services within the network.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li><i>Opportunities for supernumerary clinical practice will normally be in high volume or more specialist services. These may be supported by the use of 'Certificates of Fitness for Honorary Practice and 'NHS Education Passports'.</i></li> </ol>
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<h3 style="color: #00A68F;">Service Organisation and Liaison with Other Services</h3>						
PY-601 <table border="1" data-bbox="204 842 284 983"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Care Package Review Board</b></p> <p>A Network Care Package Review Board should offer multi-professional and multi-agency advice on care package decisions to local commissioners.</p> <p><i>Notes:</i></p> <ol style="list-style-type: none"> <li><i>The Network may cooperate with other Networks in running this Review Board.</i></li> </ol>
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PY-602  <table border="1" data-bbox="204 293 284 434"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Discharge Planning – Network Guidelines</b></p> <p>The Network should have agreed guidelines covering:</p> <ol style="list-style-type: none"> <li>a. Notifying the relevant commissioner as soon as long-term ventilation is considered</li> <li>b. Agreement with the commissioner of the Home Support Service which should be involved in the pre-discharge assessment of the child*</li> <li>c. Arrangements for the Home Support Service to meet the child and their family*</li> <li>d. Involvement of the child and their family in planning to go home</li> <li>e. Arranging multi-disciplinary meetings to discuss the discharge Care Package involving at least*:             <ol style="list-style-type: none"> <li>i. Child and their parents (unless other arrangements agreed)*</li> <li>ii. The child’s general practitioner*</li> <li>iii. The child’s nominated Community Children’s Nurse (QS 0)*</li> <li>iv. Lead Clinician (QS PP-201) and appropriate other staff from the Home Support Service *</li> <li>v. Lead consultant, ‘key worker’* and appropriate other staff from the Tertiary Children’s LTV Service*</li> <li>vi. Allied healthcare professionals involved with the care of the child</li> <li>vii. Appropriate social care representative*</li> <li>viii. Continuing care representative (nominated children and young people’s health assessor) *</li> </ol> </li> <li>f. Documenting agreements reached at multi-disciplinary meetings, including weekly evaluation and reporting of medical stability and readiness for discharge*</li> <li>g. Ensuring multi-disciplinary review at least monthly between medical stability and discharge*</li> <li>h. Assessment by the Home Support Service*, including:             <ol style="list-style-type: none"> <li>i. Assessment while at hospital</li> <li>ii. Daytime and overnight visits home and phased transition home</li> <li>iii. Proposed care package, including staff, equipment and consumables</li> </ol> </li> <li>i. Agreement of proposed care package by the child, their family, Tertiary Children’s LTV Service, Home Support Service which will be providing post-discharge care and commissioners*</li> <li>j. Involvement of the local education service and agreement of an Education Health Care Plan</li> <li>k. Consideration of housing and any housing adaptations needed*</li> <li>l. Preparation for discharge including ‘Step Down’ care (if appropriate) and staff and family training</li> <li>m. Communication to all services involved with the care of the child, including the acute Trust nearest their home, ‘Step Down’ service (if applicable) and their school</li> <li>n. Support during the time immediately after discharge</li> <li>o. Review of the care package and continuing care assessment at three and six months after discharge (note 1)</li> <li>p. Expected timescales for the discharge process (note 2)</li> </ol>
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	<p><i>Notes:</i></p> <p>6. <i>Ongoing review of the care package and continuing care assessment is covered by QS 0.</i></p> <p>7. <i>Desirable timescales are:</i></p> <ul style="list-style-type: none"> <li>• <i>Agreement by commissioners of the Home Support Service to be involved in pre-discharge assessment within one week of the decision that long-term ventilation may be needed</i></li> <li>• <i>Multi-disciplinary meeting to discuss discharge within two weeks of the commissioner's decision</i></li> <li>• <i>Full assessment and care package proposed within six weeks of the multi-disciplinary meeting (as required by the National Framework for Children's Continuing Care)</i></li> </ul> <p>8. <i>Agreement of commissioners to the Network guidelines is covered in QS PZ-604. Notifying relevant commissioners may not be needed for children with level 1 care if appropriate agreements are in place.</i></p> <p>9. <i>Comprehensive guidance on the discharge management and community support for children needing long-term ventilation is given in the Barnardo's publication 'From Hospital to Home: Guidance on discharge management and community support for children using long-term ventilation' (Noyes &amp; Lewis, 2005) which includes an exemplar outlining the full care pathway through to providing on-going care in the home care setting and then to transition to adult services. Further guidance on discharge planning is given in the 'Children's Long-Term Ventilation Discharge Planning Guide' NHS England, Leicestershire &amp; Lincolnshire Area Team, 2013, or the Royal Brompton &amp; Harefield NHS Foundation Trust 'Hospital to Home Pathway' videos</i>  <a href="https://hospitaltohome.nhs.uk/">https://hospitaltohome.nhs.uk/</a>  <i>Full references are given in Appendix 2.</i></p>					
<p>PY-603</p> <table border="1" data-bbox="204 1088 284 1227"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>'Cross-Service' Working</b></p> <p>Arrangements for staff to work in other services should be agreed by the Network, covering at least:</p> <ol style="list-style-type: none"> <li>a. Situations when staff working in other services will be considered</li> <li>b. Honorary contracts</li> <li>c. Disclosure and Barring Service (DBS) checks</li> <li>d. Additional travel time</li> <li>e. Travel expenses</li> <li>f. Local induction</li> <li>g. Ensuring staff work within their areas of competence</li> <li>h. Payment arrangements</li> <li>i. Transfer of competency training records</li> <li>j. Arrangements for ongoing clinical supervision</li> </ol> <p><i>Notes:</i></p> <p>10. <i>The purpose of this QS is both to maximise continuity of care for individual children and to ensure the best use is made of the pool of staff with competences in the care of children needing long-term ventilation.</i></p>
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<p>PY-604</p> <table border="1" data-bbox="204 1727 284 1865"> <tr><td>BI</td></tr> <tr><td>Visit</td></tr> <tr><td>MP&amp;S</td></tr> <tr><td>CNR</td></tr> <tr><td>Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<p><b>Accessing Tertiary LTV Service</b></p> <p>Indications and arrangements for accessing the Tertiary LTV Service should be agreed by the Network and circulated by the Tertiary LTV service to all Home Support Services and to acute paediatric services within the Network.</p>
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<b>Governance</b>						
PY-702 <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="text-align: center;">BI</td></tr> <tr><td style="text-align: center;">Visit</td></tr> <tr style="background-color: #e6f2ff;"><td style="text-align: center;">MP&amp;S</td></tr> <tr><td style="text-align: center;">CNR</td></tr> <tr style="background-color: #e6f2ff;"><td style="text-align: center;">Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<b>Network Audit</b>  The Network should agree a programme of network-wide audits.
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PY-798 <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="text-align: center;">BI</td></tr> <tr><td style="text-align: center;">Visit</td></tr> <tr style="background-color: #e6f2ff;"><td style="text-align: center;">MP&amp;S</td></tr> <tr><td style="text-align: center;">CNR</td></tr> <tr style="background-color: #e6f2ff;"><td style="text-align: center;">Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<b>Network Review and Learning</b>  At least annually, the Network should run a Network-wide training event, including multi-disciplinary clinical case review, with the aim of identifying improvements which can be made by services across the network.  <i>Notes:</i> <i>11. It is desirable that the network also has arrangements for multi-disciplinary review of, and implementing learning from, positive feedback, complaints, morbidity, mortality, transfers and clinical incidents and 'near misses'.</i>
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## Commissioning

Ref	Standard					
<b>Service Organisation and Liaison with Other Services</b>						
PZ-603 <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="background-color: #4a4a8a; color: white;">BI</td></tr> <tr><td style="background-color: #4a4a8a; color: white;">Visit</td></tr> <tr><td style="background-color: #4a4a8a; color: white;">MP&amp;S</td></tr> <tr><td style="background-color: #4a4a8a; color: white;">CNR</td></tr> <tr><td style="background-color: #4a4a8a; color: white;">Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<b>Commissioning: Long-Term Ventilation for Children and Young People</b> Services to meet the needs of children and young people on long-term ventilation should be commissioned, including: <ol style="list-style-type: none"> <li>a. Tertiary Children’s LTV Service</li> <li>b. ‘Step-Down / Short Break’ Service</li> <li>c. Home Support Service/s</li> <li>d. Regional Children’s LTV Network</li> </ol> The model of services commissioned should take into account sustainability of service quality. Criteria and arrangements for referral to and discharge from each service should be specified.  <i>Notes:</i> 12. This QS is applicable to care commissioned through Personal Health Budgets.
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PZ-604 <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="background-color: #4a4a8a; color: white;">BI</td></tr> <tr><td style="background-color: #4a4a8a; color: white;">Visit</td></tr> <tr><td style="background-color: #4a4a8a; color: white;">MP&amp;S</td></tr> <tr><td style="background-color: #4a4a8a; color: white;">CNR</td></tr> <tr><td style="background-color: #4a4a8a; color: white;">Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<b>Discharge Planning Guidelines</b> Commissioners should agree the Children’s Long-Term Ventilation Network guidelines on discharge from hospital (QS PY-602).  <i>Notes:</i> 13. QS PY-602 Note 4 gives more detail of available guidance on discharge from hospital.
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PZ-605 <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="background-color: #4a4a8a; color: white;">BI</td></tr> <tr><td style="background-color: #4a4a8a; color: white;">Visit</td></tr> <tr><td style="background-color: #4a4a8a; color: white;">MP&amp;S</td></tr> <tr><td style="background-color: #4a4a8a; color: white;">CNR</td></tr> <tr><td style="background-color: #4a4a8a; color: white;">Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<b>Education of Children and Young People on Long-Term Ventilation (Level 2/3 only)</b> 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, in particular: <ol style="list-style-type: none"> <li>a. Arrangements for liaison with schools and colleges</li> <li>b. Agreement of an Education Health Care Plan for each child (QS 0)</li> <li>c. Visits to the school by relevant staff to discuss the care of each child starting long-term ventilation</li> <li>d. Responsibilities of school staff in the care of the child</li> <li>e. Training and assessment of competences of school staff in these responsibilities</li> <li>f. Disposal of clinical waste (if applicable)</li> </ol> <i>Notes:</i> 14. Agreements with Local Education Authorities may be different in each Clinical Commissioning Group area.
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PZ-701 <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="background-color: #4a4a8a; color: white;">BI</td></tr> <tr><td style="background-color: #4a4a8a; color: white;">Visit</td></tr> <tr><td style="background-color: #4a4a8a; color: white;">MP&amp;S</td></tr> <tr><td style="background-color: #4a4a8a; color: white;">CNR</td></tr> <tr><td style="background-color: #4a4a8a; color: white;">Doc</td></tr> </table>	BI	Visit	MP&S	CNR	Doc	<b>Quality Monitoring: Children’s Long-Term Ventilation Services</b> Commissioners should regularly review the quality of services provided by children’s long-term ventilation services (QS PP-701). Appropriate action should be taken to tackle any issues identified through quality monitoring.  <i>Notes:</i> 15. This QS is applicable to care commissioned through Personal Health Budgets.
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## APPENDIX 1 Steering Group Membership

Name	Organisation
Jill Bloxham	Coventry and Warwickshire Partnership NHS Trust
Isobel Brookes	Birmingham Children's Hospital NHS Foundation Trust
Kay Calvert	University Hospital of Leicester NHS Trust
Jane Clarke	Birmingham Children's Hospital NHS Foundation Trust
Joanne Claymore	Coventry and Warwickshire Partnership NHS Trust
Victoria Derricutt	South Staffordshire and Shropshire NHS Foundation Trust
Vicky Elliot	University Hospital of Leicester NHS Trust
Teresa Evans	Birmingham Children's Hospital NHS Foundation Trust
Adele Frost	Nottingham Children's Hospital, Nottingham University Hospitals NHS Trust
Rachael Gregory	Nottingham Children's Hospital, Nottingham University Hospitals NHS Trust
Sam Harris	South Warwickshire NHS Foundation Trust
Liz Herd	South Warwickshire NHS Foundation Trust
Melanie Hyland	South Warwickshire NHS Foundation Trust
Kamini Jain	University Hospital of Leicester NHS Trust
Sara Kirby	Acorns Children's Hospice
Tammy Neale	Parent
Audrey Martin	Birmingham Children's Hospital NHS Foundation Trust
Jo Matthews	Birmingham Children's Hospital NHS Foundation Trust
Nicola McNarry	Nottingham Children's Hospital, Nottingham University Hospitals NHS Trust
Ryan Rukas	South Staffordshire and Shropshire NHS Foundation Trust
Annika Shepherd	Coventry and Warwickshire Partnership NHS Trust
Rebecca Silcock	Nottingham University Hospitals NHS Trust
Gustavo Taramasco	Birmingham Children's Hospital NHS Foundation Trust
Rachel Toogood	Birmingham Children's Hospital NHS Foundation Trust
Ruth Wall	Birmingham Children's Hospital NHS Foundation Trust
Joanne Watson (Joint Chair)	Derbyshire Children's Hospital, Derby Teaching Hospitals NHS Foundation Trust
David Widdas (Joint Chair)	South Warwickshire NHS Foundation Trust
Jane Eminson	West Midlands Quality Review Service
Sarah Broomhead	West Midlands Quality Review Service

## APPENDIX 2 Appendix 1b Standards Development Group (2015)

Name	Organisation
David Widdas (Chair)	South Warwickshire NHS Foundation Trust
Jill Bloxham	Coventry and Warwickshire Partnership NHS Trust
Jane Clarke	Birmingham Children's Hospital NHS Foundation Trust
Joanne Claymore	Birmingham Children's Hospital NHS Foundation Trust
Stephanie Courts	Worcestershire Acute Hospitals NHS Trust
Victoria Derricutt	Staffordshire and Stoke on Trent Partnership NHS Trust
Sam Harris	South Warwickshire NHS Foundation Trust
Liz Herd	Coventry and Warwickshire Partnership NHS Trust
Joe Holder	South Warwickshire NHS Foundation Trust
Melanie Hyland	South Staffordshire and Shropshire Healthcare NHS Foundation Trust
Melanie McFeeters	NHS England
Gustavo Taramasco	Birmingham Children's Hospital NHS Foundation Trust
Ruth Wall	Birmingham Children's Hospital NHS Foundation Trust
Joanne Watson	Birmingham Children's Hospital NHS Foundation Trust
Jane Eminson	West Midlands Quality Review Service

## Pathfinder Working Group (2015)

Name	Organisation
Rachel Gregory	Nottingham University Hospitals NHS Trust
Elspeth Jardine	NHS Greater Glasgow and Clyde
Jo Matthews	Birmingham Children's Hospital NHS Foundation Trust
Melanie McFeeters	NHS England
Linda Partridge	WellChild
Andrew Selby	Alder Hey Children's NHS Foundation Trust
Ruth Wakeman	Royal Brompton and Harefield NHS Foundation Trust
Joanne Watson	Birmingham Children's Hospital NHS Foundation Trust
David Widdas	South Warwickshire NHS Foundation Trust

## APPENDIX 3 Reference Sources

	Year	Title	No.
Accessed 2018	Royal Brompton & Harefield NHS Foundation Trust	'Hospital to Home Pathway' videos <a href="https://hospitaltohome.nhs.uk/">https://hospitaltohome.nhs.uk/</a>	45
2017	NHS Improvement	Developmental Reviews of Leadership and Governance using the Well-led Framework: Guidance for NHS Trusts and NHS Foundation Trusts	44
2016	National Institute for Health and Care Excellence	Transition from children's to adults' services NG43	43
2014	Department of Health <a href="http://www.personalhealthbudgets.dh.gov.uk/Toolkit">www.personalhealthbudgets.dh.gov.uk/Toolkit</a>	Personal Health Budgets Toolkit. Learning from the pilot program	42
2014	Department for Education <a href="http://www.gov.uk/government/publications/supporting-pupils-at-school-with-medical-conditions">www.gov.uk/government/publications/supporting-pupils-at-school-with-medical-conditions</a>	Supporting pupils at school with medical conditions. Statutory guidance for governing bodies of maintained schools and proprietors of academies in England.	41
2014	The Patient Experience Network	Children who are Long Term Ventilated – Pathfinder Project Engaging with Families and Children / Young People An independent quality improvement review by the Patient Experience Network for NHS England, prepared by Ruth Evans	40
2013	Together for Short Lives	A Core Care Pathway for children with Life-Limiting and Life-Threatening Conditions	39
2013	NHS England	Service Specification: Paediatric Long-Term Ventilation	38
2013	NHS England, Leicestershire & Lincolnshire Area Team	Children's Long Term Ventilation Discharge Planning Guide	37
2012	Royal College of Nursing	Defining staffing levels for children and young people's services. RCN Standards for clinical professionals and service managers	36
2012	<a href="http://www.learningdisabilities.org.uk/our-news/30-may-2012">www.learningdisabilities.org.uk/our-news/30-may-2012</a>	An Ordinary Life: supporting families whose child is dependent on medical technology or has complex health needs'. Foundation for people with learning disabilities	35
2012	Disability Rights UK <a href="http://www.disabilityrightsuk.org/how-we-can-help/independent-living/how-to-take-control-your-disabled-child%E2%80%99s-care-giving-you-more">http://www.disabilityrightsuk.org/how-we-can-help/independent-living/how-to-take-control-your-disabled-child%E2%80%99s-care-giving-you-more</a>	How to take control of your disabled child's care. Giving you more choice with personal budgets	34
2012	Department of Health	Personal Health Budgets Guide. Personal Assistants: delegation, training and accountability	33

2012	Department of Health	Personal Health Budgets Guide. Implementing effective care planning	32
2011	The Council for Disabled Children	Managing My Way	31
2011	Children's Hospices UK.	A Guide to Support Ventilated Children & Young People in Children's Hospices	30
2011	Epub	Children on long-term ventilatory support: 10 years of progress	29
2011	Department of Health	You're Welcome - Quality criteria for young people friendly health services	28
2011	Journal of Family Nursing	Family Members' Experiences of Everyday Life when a Child is dependent on a ventilator: A metasynthesis study: K Dybwik, EW Nielsen, BS Brinchmann	27
2011	BMC Health Services Research	Home mechanical ventilation and specialised health care in the community: between a rock and a hard place	26
2010	London: National Children's Bureau	Guidelines on the discharge from hospital of children and young people with high support needs'	25
2010	Department of Health	National Framework for Children and Young People's Continuing Care	24
2010	Department of Health	Getting it Right for Children and Young People. Overcoming cultural barriers in the NHS so as to meet their needs. A Review by Professor Ian Kennedy	23
2009	The NHS Confederation	Aiming high for disabled children: delivering improved health services'	22
2007	Bristol. ACT	The Transition Care Pathway. A Framework for the development of Integrated Multi-Agency Care Pathways for Young People with Life-threatening and Life-Limiting Conditions	21
2007	Department for Education and Skills	Aiming high for disabled children: better support for families	20
2006	Journal of Advanced Nursing	Comparison of ventilator-dependent child reports of health-related quality of life with parents reports and normative populations	19
2005	Barnardo's	From Hospital to Home: Guidance on discharge management and community support for children using long-term ventilation'	18
2005	Health and Social Care in the Community	Families' experiences of caring for technology-dependent children: a temporal perspective	17
2005	Elsevier	Textbook of community Children's Nursing. Second Edition'	16

2005	Department for Education and Skills	Including me. Managing complex health needs in schools and early years settings	15
2004	Archives of Disease in Childhood	Sending children home on tracheostomy dependent ventilation: pitfalls and outcomes	14
2004	Journal of Advanced Nursing	Parent or Nurse? The experience of being the parent of a technology-dependent child.	13
2004	Department of Health	National Service Framework for Children, Young People and Maternity Services'	12
2004	Child: Care, Health & Development	Parental experience of services when their child requires long-term ventilation. Implications for commissioning and providing services	11
2003	Child: Care, Health & Development	Developing services to support parents caring for technology-dependent child at home	10
2003	Children and Society	Children and Young People requiring Home Assisted Ventilation in the South of England: Incidence Receipt of Care Support and Components of Care Package; AE White, AM Cockett, S Lewis	9
2003	Department for Education and Skills	Every Child Matters	8
2001	The Stationary Office	Learning from Bristol. The Report of the Public Inquiry into children's heart surgery at the Bristol Royal Infirmary 1984-1995	7
2001	Journal of Clinical Nursing	'The experiences and views of parents who care for ventilator-dependent children' by J Noyes, H Hartmann, M Samuels D Southall	6
2000	Department of Health	Framework for the Assessment of Children in need and their Families	5
1999	The Stationery Office	Voices and Choices. Young People Who Use Assisted Ventilation: Their Health and Social Care, and Education	4
1999	British Medical Journal	Current Status of Long Term Ventilation of Children in the United Kingdom: Questionnaire Survey	3
1994	Elsevier	Textbook of Community Children's Nursing. Second Edition	2

The table below shows the links between the Quality Standards and generic guidance documents. Quality Standards without a reference source are based on other QRS Quality Standards, taking into account comments received.

QS reference	Guidance documents	QS reference	Guidance documents	QS reference	Guidance documents
PP-101	5,12,15,18,20,28	PP-207	7,23,36	PP-610	
PP-102	11,12,13,17,19,25,28,34,35,39,40,42	PP-208	18,33,39	PP-701	7,12,23,32,33,35,44
PP-103	12,18,19,25,38,39,40	PP-209	36	PP-702	7,12,23,32,33,35,44
PP-104	6,19,24,25,27,38,40	PP-299	18	PP-798	6,44
PP-105	8,10,11,12,18,35,38,39,40	PP-301	8,12,15,30,39	PP-799	
PP-106	8,10,12,15,18,36,39	PP-302	18,39	PY-101	28
PP-107	16,18,40	PP-303	25,39	PY-199	28,40
PP-108	18,20,28,31,39	PP-304	38	PY-201	18,23,36,44
PP-109	8, 10,15,20,22,27,31	PP-401	14,18,25	PY-203	15,22,38,44
PP-110	12	PP-501	6,38,40	PY-204	7,12,15,18,22,23,30,33,38,44
PP-111	12	PP-502	22	PY-601	9,24,38
PP-112	12,13,38,40	PP-601	6,7,23,25,37,38,44	PY-602	6,9,14,18,24,25,37,38,39,45
PP-196	10,12,27	PP-602	6,14,18,24,25,37,38,39,45	PY-603	6,38,43,44
PP-199	10,11,12,20,27,28,35,39,40	PP-603	14,15,18,20,24,25,32,35,36,39	PY-702	7,44
PP-201	18,23,36,44	PP-604	7,23,24,36,	PY-798	23,44
PP-202	7,12,23,25,36,44	PP-605	38,40	PZ-603	19,29,38,40
PP-203	7,12,14,23,25,30,36,38,39,44	PP-606	18	PZ-604	24,25,37,38
PP-204	7,12,15,18,22,23,30,33,38,40,44	PP-607	18	PZ-605	8,15,39,41
PP-205	7,18,23,25,30,36,39,40,44	PP-608	6,18,21,29,40,43	PZ-701	
PP-206	33,36,40	PP-609	8,12,15,22,39,40		



## APPENDIX 4 Cross-References to British Standards Institution PAS16:16 and Care Quality Commission Key Lines of enquiry

The tables below show with an 'x' where a QRS Quality Standard addresses one of the following:

### 1. British Standards Institution PAS1616:2016 Healthcare – Provision of Clinical Services Specification

Ref	Requirements for the provision of clinical services
3	Leadership, strategy and management
4	Operational delivery of the clinical service
5	Systems to support clinical service delivery
6	Person-centred treatment and/or care
7	Risk and safety
8	Clinical effectiveness
9	Clinical service users with complex needs
10	Staffing a clinical service
11	Improvement, innovation and transformation
12	Educating the future workforce

### 2. Care Quality Commission's Key Lines of Enquiry (June 2017)

Ref	CQC Five Key Line of Enquiry
S	Are they safe?
E	Are they effective?
C	Are they caring?
R	Are they responsive?
W	Are they well-led?



Ref	British Standards Institute PAS 1616: 2016 3-12	CQC Five Key of Enquiry Questions																															
		Safe					Effective						Caring			Responsive				Well-Led													
		S 1	S 2	S 3	S 4	S 5	S 6	E 1	E 2	E 3	E 4	E 5	E 6	C 1	C 2	C 3	R 1	R 2	R 3	R 4	W 1	W 2	W 3	W 4	W 5	W 6	W 7	W 8					
PP-401	5,7	x		x				x		x						x	x	x															
PP-501	6,8,9		x					x								x	x																
PP-502	6,8,9	x	x					x				x	x	x	x																		
PP-601	6, 7, 8, 9, 10, 11, 12		x	x		x	x	x		x	x	x		x	x		x	x	x					x	x								
PP-602	6,8,9			x	x			x				x				x				x	x												
PP-603	6,8,9		x	x				x				x	x	x	x	x				x	x					x							
PP-604	6,8,9,10		x	x				x				x	x	x	x	x				x	x					x							
PP-605	6,8,9,		x	x				x				x	x	x	x	x				x	x					x							
PP-606	5,6,7,8,9	x		x				x												x	x	x											
PP-607	5,6,7,8,9	x		x				x												x	x	x					x						
PP-608	6,8,9		x	x	x			x				x				x				x													
PP-609	4, 6,9		x	x				x				x	x	x	x	x				x	x						x						
PP-610	3,4,8,10						x					x													x	x	x		x	x			
PP-701	3.2, 4, 7, 8,11			x		x	x	x	x											x							x	x	x	x	x		
PP-702	3.2, 4, 7, 8,11					x	x	x	x											x							x	x	x	x	x		
PP-798	3.2, 4, 7, 8,11				x	x	x	x	x																		x			x	x	x	
PP-799	5			x																													
PY-101	3,4,6,8,9,	x			x			x					x	x	x	x																	
PY-199	3, 7, 6	x						x																							x		
PY-201	3, 4,10,12		x					x				x															x			x			
PY-203	4, 10, 11,12		x					x	x			x															x	x	x				
PY-204	4, 10, 11,12		x					x	x			x															x	x	x				
PY-601	6,8,9			x				x								x				x	x										x		
PY-602	6,8,9			x	x			x				x								x													
PY-603	10,11	x	x					x				x			x												x	x	x				
PY-604	6,8,9		x					x												x													
PY-702	3.2, 4, 7, 8,11					x	x	x	x																			x	x	x	x	x	
PY-798	3.2, 4, 7, 8,11				x	x	x	x	x																							x	

Ref	British Standards Institute PAS 1616: 2016 3-12	CQC Five Key of Enquiry Questions																										
		Safe					Effective						Caring			Responsive				Well-Led								
		S 1	S 2	S 3	S 4	S 5	S 6	E 1	E 2	E 3	E 4	E 5	E 6	C 1	C 2	C 3	R 1	R 2	R 3	R 4	W 1	W 2	W 3	W 4	W 5	W 6	W 7	W 8
PZ-603	3,6,7,8,9,10,11			x	x			x			x	x					x	x	x			x		x				
PZ-604	6,8,9		x	x				x							x													
PZ-605	5,6,7,9,10,12	x	x					x		x		x	x									x	x		x	x		
PZ-701	3.2, 4, 7, 8,11					x	x	x	x											x				x	x	x	x	X

## APPENDIX 5 Glossary of Terms and Abbreviations

Glossary of terms and abbreviations	
<b>ACT</b>	Association for Children's Palliative Care - Together for Short Lives
<b>Advocacy</b>	Advocacy means to speak up for someone. It is about making things change because people's voices are heard and listened to. It is about making sure that people can make their own choices in life and have the chance to be as independent as they want to be.
<b>Allied Health Professionals</b>	Occupational therapy, play specialist, speech and language therapy, physiotherapy (both neuromuscular and respiratory as required) and psychology
<b>BI</b>	Background information to review team.
<b>Carer</b>	Throughout the Quality Standards the term 'carer' applies to both family carers and paid carers or support workers.
<b>CCG</b>	Clinical Commissioning Group.
<b>Child</b>	Throughout the Quality Standards the term 'child' is used to refer to babies, children and young people.
<b>Commissioner</b>	A commissioner decides how NHS and / or social care resources are spent, with the aim of improving health, reducing inequalities, and enhancing patient experience.
<b>Community Children's Nurse</b>	A registered nurse working in the community who has responsibility for liaison with local services as required. This nurse may also be the 'key worker'. Quality Standard PP-203 expects that a minimum of 75% nurses working in a long-term ventilation service will be children's trained nurses and so it is likely that the community children's nurse will be children's trained. Adult trained nurses taking this role should have appropriate competences in the care of children and young people (QS PP-204).

Glossary of terms and abbreviations	
<b>CNR</b>	Case note review or clinical observation.
<b>CQC</b>	The Care Quality Commission is the independent regulator of health and social care in England.
<b>DBS</b>	Disclosure and Barring Service
<b>DH</b>	Department of Health.
<b>Doc</b>	Documentation should be available. Documentation may be in the form of a website or other social media.
<b>ENT</b>	Ear, Nose and Throat (Otorhinolaryngology)
<b>GP</b>	A GP is a medical doctor, sometimes called a family doctor. They are usually the first person patients see for their health care, and they help patients to access other services.
<b>HealthWatch</b>	The 'consumer champion' for both health and adult social care and should be the independent, influential and effective local voice of the public on health issues.
<b>HDU</b>	High Dependency Unit
<b>Key working</b>	<p>Extract from 'Promoting key working and improving outcomes for all' - Summary Briefing (Together for Short Lives, Early Support and CLIC Sargent; April 2012):</p> <ul style="list-style-type: none"> <li>• Key working provides a navigator, an enabler, a coordinator. The overall aim of key working is to ensure the provision of holistic care and support to meet the individual needs of the child and their family.</li> <li>• We feel that much of the confusion and lack of clarity is created by referring to key working as if it is always defined by a key worker role. We feel it is more useful to define key working by a set of functions rather than defining it as a key worker role. With this approach, the model can then be applied to meet the needs of specific groups.</li> <li>• The function of key working should be defined as: <ul style="list-style-type: none"> <li>○ Being a single point of regular and consistent contact for the child, young person and family</li> <li>○ Providing information and signposting where necessary</li> <li>○ Identifying the strengths and needs of all family members</li> <li>○ Advocating on the child's, young person's and/or family's behalf where appropriate</li> <li>○ Providing emotional and practical support as required, as part of a trusting relationship</li> <li>○ Coordinating services and practitioners around the child, young person and family</li> <li>○ Facilitating multiagency meetings</li> <li>○ Supporting a single planning and joint assessment process</li> <li>○ Enabling and empowering the child, young person and their family to make decisions and use their personalised budgets in a way that is most effective for them</li> </ul> </li> </ul> <p>Facilitating clinical care seamlessly integrated with specialist and universal services, where appropriate.</p>
<b>Key Lines of Enquiry</b>	Five key questions, which CQC use to help establish whether a service is providing the high standard of care expected of them.
<b>LBR</b>	Learning beyond registration.
<b>Long-Term Ventilation</b>	"Any child when medically stable requiring a mechanical aid for breathing after an acknowledged failure to wean [off the ventilator], or slow wean, three months after institution of ventilation" (Jardine et al (1998)). This includes children needing long-term invasive or non-invasive ventilation.

Glossary of terms and abbreviations	
<b>LTV AHP</b>	The Long-Term Ventilation Allied Health Professionals may be part of the acute team, specific long-term ventilation or community team. They should have a robust understanding of, and experience in, managing the additional needs of the child / young person on ventilation. Children and young people and their families should be able to access this support in all environments (acute, community, home etc.).
<b>LTV ANP</b>	The Long Term Ventilation Advanced Nurse Practitioner may be part of the acute team, specific long-term ventilation, community team or continuing care team. They should have a robust understanding of, and experience in, managing the additional needs of the child / young person on ventilation. Children and young people and their families should be able to access this support in all environments (acute, community, home etc.).
<b>MP&amp;S</b>	Meeting patients, carers and staff.
<b>NICE</b>	National Institute for Health and Care Excellence.
<b>NHSLA</b>	NHS Litigation Authority
<b>NHS England and NHS Improvement</b>	These two organisations work together and are at the head of the NHS in England. They set and drive delivery of NHS priorities that respond to the Government's strategic goals for health and care.
<b>NVQ</b>	National Vocational Qualification.
<b>PALS</b>	Patient advice and liaison service
<b>PDR</b>	Performance Development Review.
<b>PICU</b>	Paediatric Intensive Care Unit
<b>Provider</b>	A health or social care organisation which provides services to patients.
<b>QRS</b>	Quality Review Service
<b>QS</b>	Quality Standard.
<b>RCN</b>	Royal College of Nursing
<b>RQF</b>	Regulated Qualifications Framework
<b>Service provider</b>	See 'Provider'.
<b>Service commissioner</b>	See 'Commissioner'.
<b>Trust</b>	A NHS Trust, NHS Foundation Trust or other organisation with management responsibility for the service.

## APPENDIX 6 Presentation of Evidence for Peer Review Visits

Each Quality Standard reference column includes a box which illustrates how compliance will be reviewed.

Quality Standard reference column	
<b>Background information</b>	This means that the information should be included in the background report or self-assessment.
<b>Visiting facilities</b>	Reviewers will look for the information while they are visiting the service.
<b>Meeting patients, carers and staff</b>	These Standards will be discussed with patient, carers and /or staff as appropriate.
<b>Case note review or clinical observation</b>	A few Quality Standards require reviewers to look at case notes or other clinical information.
<b>Documentation</b>	These are policies, guidelines and other documentation that reviewers will need to see. Documentation may be in the form of a website or other social media.

The following table summarises the evidence needed for each Quality Standard.

QS Ref. No	QS Short Title	Background Report	Visit	Meeting Patients & Staff	Case Note Review	Documentation	Illustration of Documentation Required
		BI	Visit	MP&S	CNR	DOC	
PP-101	Service Information		X	X		X	Information about the service
PP-102	Information about Long-Term Ventilation		X	X		X	Examples of condition specific information
PP-103	Personalised Care Plan			X	X		
PP-104	Formal Reviews of Care Plan and Continuing Care Assessment			X	X		
PP-105	'Key Worker' (Level 2/3 only)			X	X		
PP-106	Community Children's Nurse			X	X		
PP-107	Agreement of Care (Level 2/3 only)			X	X		
PP-108	Education Health Care Plan			X	X		
PP-109	Self-Care and Family Involvement in Care			X	X		
PP-110	Facilities for Families		X	X			



QS Ref. No	QS Short Title	Background Report	Visit	Meeting Patients & Staff	Case Note Review	Documentation	Illustration of Documentation Required
		BI	Visit	MP&S	CNR	DOC	
PP-111	Play Support	X	X	X			
PP-112	Support for Families						
PP-196	General Support for Children and their Families		X	X			
PP-199	Involving Children, Young People and Families			X		X	Examples of changes made as a result of feedback
PP-201	Clinical Leadership	X					
PP-202	Staffing Levels – Tertiary Children’s LTV Services	X		X			
PP-203	Staffing Levels – Home Support and ‘Step Down / Short Break’ Services	X		X			
PP-204	Competence Framework and Training Plan			X		X	<b>Competence Framework and Training Plan:</b> <ul style="list-style-type: none"> <li>Competence framework describing the competences expected for roles within the service.</li> <li>Training and development plan to show how staff will achieve and maintain competences</li> </ul>
PP-205	24/7 Children’s Nursing Support (Level 2/3 only)	X		X			
PP-206	Observation of Practice	X		X			
PP-207	Tertiary LTV Advice Service	X		X			
PP-208	Emotional Support for Staff			X			
PP-209	Clinical Supervision			X			
PP-299	Administrative and Clerical Support	X		X			
PP-301	Support Services – Home Support and ‘Step Down / Short Break’ Services	X		X			

QS Ref. No	QS Short Title	Background Report	Visit	Meeting Patients & Staff	Case Note Review	Documentation	Illustration of Documentation Required
		BI	Visit	MP&S	CNR	DOC	
PP-302	Other Services Providing Support Where Care is Delivered	X		X			
PP-303	Other Support Services	X		X			
PP-304	Support Services – Tertiary Children’s LTV Services	X		X			
PP-401	Equipment		X	X			
PP-501	Guidelines on Initiation of Ventilation			X		X	<b>Guidelines:</b> Initiation of ventilation
PP-502	Clinical Guidelines			X		X	<b>Guidelines:</b> Clinical
PP-601	Service Organisation			X		X	Operational Procedure
PP-602	Discharge Guidelines			X		X	<b>Guidelines:</b> Discharge Planning
PP-603	Multi-Agency Care Planning Policy			X	X	X	<b>Policy:</b> Multi-agency care planning and continuing care assessments
PP-604	Weekly Review (Level 2/3 only)			X	X		
PP-605	Guidelines on Communication with Ambulance Service			X		X	<b>Guidelines:</b> Communication with the Ambulance Service
PP-606	Equipment Policy			X		X	<b>Guidelines:</b> Equipment
PP-607	Equipment Responsibilities			X		X	Equipment Register
PP-608	Transition Guidelines			X		X	<b>Guidelines:</b> covering transition from neonatal care to children’s services or from children’s services to adult care
PP-609	Liaison with Support Services			X		X	Documentation depends on local arrangements, for example, minutes of meetings held with key services
PP-610	Children’s Long-Term Ventilation Network			X		X	Examples showing attendance at network meetings.
PP-701	Data Collection			X		X	Examples of data showing compliance with the QS
PP-702	Audit			X		X	Audit programme or plan Examples of completed audits, action plans and monitoring.

QS Ref. No	QS Short Title	Background Report	Visit	Meeting Patients & Staff	Case Note Review	Documentation	Illustration of Documentation Required
		BI	Visit	MP&S	CNR	DOC	
PP-798	Review and Learning			X		X	Documentation depends on local arrangements, for example, minutes of review and learning meetings held within the service.
PP-799	Document Control					X	Organisations document control policies and compliance determined from documentation presented.
PY-101	Network Information for Families			X		X	Information for families
PY-199	Involving Children and Families			X		X	Examples of changes made as a result of feedback
PY-201	Network Lead Clinician	X		X			
PY-203	Network Competences			X		X	Agreed Network competence framework describing the competences expected for roles for LTV services.
PY-204	Network Wide Training and CPD			X		X	Details of network training schedule
PY-601	Care Package Review Board			X		X	Documentation depends on local arrangements, for example, minutes of review board minutes
PY-602	Discharge Planning – Network Guidelines			X		X	<b>Guidelines:</b> Network discharge planning
PY-603	'Cross-Service' Working			X		X	<b>Agreement:</b> 'Cross service' working
PY-604	Accessing Tertiary LTV Service			X		X	<b>Arrangements:</b> Accessing tertiary LTV services
PY-702	Network Audit			X		X	Network Audit programme or plan Examples of completed audits, action plans and monitoring.
PY-798	Network Review and Learning			X		X	Documentation depends on network arrangements, for example, minutes of review and learning meetings held within the network
PZ-603	Commissioning: Long-Term Ventilation for Children and Young People	X				X	Service Specification
PZ-604	Discharge Planning Guidelines			X		X	<b>Guidelines:</b> Network discharge planning

QS Ref. No	QS Short Title	Background Report	Visit	Meeting Patients & Staff	Case Note Review	Documentation	Illustration of Documentation Required
		BI	Visit	MP&S	CNR	DOC	
PZ-605	<b>Education of Children and Young People on Long-Term Ventilation (Level 2/3 only)</b>			X		X	Agreements with Local Education Authority
PZ-701	<b>Quality Monitoring: Children's Long-Term Ventilation Services</b>			X		X	Documentation depends on local arrangements, for example, minutes of review and learning meetings involving all local services