

Long-Term Ventilation for Children and Young People

North Staffordshire Health Economy

Visit Date: 29th April 2015

Report Date: July 2015



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INTRODUCTION

This report presents the findings of the review of Long-Term Ventilation for Children and Young People that took place on 29th April 2015. The purpose of the visit was to review compliance with the following West Midlands Quality Review Service (WMQRS) Quality Standards:

- Services providing Long-Term Ventilation for Children and Young People, Version 3 Draft, January 2015

The aim of the standards and the review programme is to help providers and commissioners of services to improve clinical outcomes and service users' and carers' experiences by improving the quality of services. The report also gives external assurance of the care, which can be used as part of organisations' Quality Accounts. For commissioners, the report gives assurance of the quality of services commissioned and identifies areas where developments may be needed.

The report reflects the situation at the time of the visit. The text of this report identifies the main issues raised during the course of the visit. Appendix 1 lists the visiting team that reviewed the services at North Staffordshire health economy. Appendix 2 contains the details of compliance with each of the standards and the percentage of standards met.

This report describes services provided or commissioned by the following organisations:

- University Hospitals of North Midlands NHS Trust (UHNM)
- Staffordshire & Stoke on Trent Partnership NHS Trust (SSOTP)
- NHS North Staffordshire CCG
- NHS Stoke on Trent CCG

Most of the issues identified by quality reviews can be resolved by providers' and commissioners' own governance arrangements. Many can be tackled by the use of appropriate service improvement approaches; some require commissioner input. Individual organisations are responsible for taking action and monitoring this through their usual governance mechanisms. The lead commissioner for the service concerned is responsible for ensuring action plans are in place and monitoring their implementation, liaising, as appropriate, with other commissioners, including commissioners of primary care. The lead commissioner in relation to this report is NHS North Staffordshire Clinical Commissioning Group.

ABOUT WEST MIDLANDS QUALITY REVIEW SERVICE

WMQRS is a collaborative venture between NHS organisations in the West Midlands to help improve the quality of health services by developing evidence-based Quality Standards, carrying out developmental and supportive quality reviews – often through peer review visits, producing comparative information on the quality of services and providing development and learning for all involved.

Expected outcomes are better quality, safety and clinical outcomes, better patient and carer experience, organisations with better information about the quality of clinical services, and organisations with more confidence and competence in reviewing the quality of clinical services. More detail about the work of WMQRS is available on www.wmqrs.nhs.uk

ACKNOWLEDGMENTS

West Midlands Quality Review Service would like to thank the staff and service users and carers of North Staffordshire health economy for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. Thanks are also due to the visiting team and their employing organisations for the time and expertise they contributed to this review.

LONG-TERM VENTILATION FOR CHILDREN AND YOUNG PEOPLE

LONG-TERM VENTILATION SERVICE

General Comments and Achievements

The paediatric long-term ventilation service in North Staffordshire and Stoke on Trent was a joint service run by University Hospitals of North Midlands NHS Trust (at the Royal Stoke Hospital site) and the Staffordshire and Stoke on Trent Partnership NHS Trust (community services). The University Hospitals of North Midlands NHS Trust also provided a tertiary children's long-term ventilation service for children and young people from Staffordshire, other parts of England and other countries. At the time of the visit, the tertiary service provided care for 60 patients, of whom 25 were from the local area. The community service provided care for between 25 and 30 children and young people who were on long-term ventilation or had other complex needs.

Only patients who met specified eligibility criteria were accepted by the service in the University Hospitals of North Midlands NHS Trust. A decision support tool was used to assess whether the eligibility criteria were met.

The University Hospitals of North Midlands NHS Trust service was provided by a paediatric respiratory consultant, ward-based staff and a nurse-led Care Coordination Team. Children needing acute hospital care were normally admitted to ward 216, situated next to the Children's Intensive Care Unit. Ward facilities for patients and their families were good. The Care Coordination Team looked after children with complex health needs, including long-term ventilation and other complex care needs, who were medically stable. The Team cared for children from birth to 17 years. The focus of the Team's work was on transition from hospital to community-based care, to allow patients either to return home or to move to a care environment with appropriate support, on a temporary or permanent basis.

The Staffordshire and Stoke on Trent Partnership NHS Trust service was provided by both the Continuing Healthcare Team and the Palliative and Complex Care Team. The previous Children's Airways Support Team (CAST) had been re-configured in April 2014 to become the Continuing Healthcare Team. This involved some changes to staff roles. Carers and patients expressed satisfaction with the level of service that had been maintained through these changes. The Trust was aware of further change needed within the service.

Good Practice

- 1 SSOTP: Information in the care plan contained very clear instructions and pictures about sleep positions for ventilated children.
- 2 UHNM: An annual 'one stop' multi-disciplinary review was in place for children and young people cared for by the service. Community staff did not attend these meetings.
- 3 SSOTP: Information for families about The HUB was very clear.

Immediate Risks: No immediate risks were identified

Concerns

1 Clinical Leadership

Clinical leadership for the service as a whole was not in place, and the expertise of the UHNM staff did not appear to be fully utilised by the community service. Clinical leadership for the SSOTP service was not clear; the service had two case managers with experience in the care of children on long-term ventilation and a non-clinical manager.

2 Care Plans

Care plans were separate in the two services, rather than a single care plan for each child. The SSOTP care plans were not signed and dated and did not contain parental agreements. The front page contained

patient details but the following pages did not contain any patient identifiable information and were not dated.

3 Data Collection and Audit

The services did not collect the data expected by the Quality Standards, and a rolling programme of audit was not in place. The SSOTP service had no staff to support data collection.

4 Staffing levels (UHNM)

The UHNM service was heavily reliant on two key individuals: a 0.6 w.t.e. clinical nurse specialist and a paediatric respiratory consultant with only 1.5 PAs per week for work with the service. Cover arrangements were not robust and it was not clear what would happen if either of the key individuals was absent for any length of time.

5 Transition

The transition process was not embedded in the service as a whole. Reviewers were told by carers and patients that they were unclear about the process of transition to adult services and about the services that would be available after transition.

6 Competence Framework and Training Plan (SSOTP)

Expected staff competences for roles within the SSOTP service were not clearly defined. There was no competence framework or overall training plan. The service was planning to implement an electronic system using the Coventry and Warwickshire Children and Young People's Competency Framework.

Further Consideration

- 1 Joint working between the UHNM and SSOTP services was not yet in place for several important aspects of care. In particular, the Quality Standards expect that each child has one care plan, one formal review, one key worker and one community children's nurse, and not that each service provides these separately.
- 2 Children and young people who needed level one care did not receive the same level of support as those needing level two and three care. It may be helpful to consider whether support for children and young people needing level 1 care can be improved. A discussion about this had been arranged.
- 3 A clear pathway for the provision of equipment and consumables was not in place and reviewers were told that delays in the supply of equipment, including consumables, for children and young people at home were being experienced. Further work in this area may be helpful.

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COMMISSIONING – NHS NORTH STAFFORDSHIRE CLINICAL COMMISSIONING GROUP AND NHS STOKE ON TRENT CLINICAL COMMISSIONING GROUP

General Comments and Achievements

The paediatric long-term ventilation service was jointly commissioned by NHS North Staffordshire Clinical Commissioning Group and NHS Stoke on Trent Clinical Commissioning Group. A full range of services was commissioned and commissioners were actively involved in discussions about the service, but some arrangements differed between the two CCGs; for example, NHS Stoke on Trent CCG had a contract for 'step down' care with the Donna Louise Trust but NHS North Staffordshire CCG arranged 'step down' care through individual funding arrangements.

Concerns

- 1 The issues identified in this report will require the engagement of commissioners to ensure they are addressed:
 - a. Clinical Leadership
 - b. Care Plans
 - c. Data Collection and Audit
 - d. Staffing levels (UHNM
 - e. Competence Framework and Training Plan

Further Consideration

- 1 Children and young people who needed level one care did not receive the same level of support as those needing level two and three care. It may be helpful to consider whether support for children and young people needing level one care can be improved. A discussion about this had been arranged.
- 2 Commissioners had not specified that the expected data should be collected in order to inform future service planning and development. Further work in this area may be helpful.

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APPENDIX 1 MEMBERSHIP OF VISITING TEAM

Visiting Team

Stephanie Courts	Children's Nurse Consultant and Complex Care Manager	Worcestershire Health & Care NHS Trust
Wendy Godwin	Lead Commissioner Planned Care	NHS Walsall CCG
Joanne Holder	Clinical Lead, Children's Community Nursing Team	South Warwickshire NHS Foundation Trust
Melanie Hyland	Trainee Advanced Nurse Practitioner for Complex Care	Birmingham Children's Hospital NHS Foundation Trust
Dr Satish Rao	Respiratory Consultant/Clinical Director for Respiratory and Related Specialties	Birmingham Children's Hospital NHS Foundation Trust

WMQRS Team

Sarah Broomhead	Assistant Director	West Midlands Quality Review Service
Sue McIldowie	Quality Manager	West Midlands Quality Review Service

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APPENDIX 2 COMPLIANCE WITH THE QUALITY STANDARDS

Analyses of percentage compliance with the Quality Standards should be viewed with caution as they give the same weight to each of the Quality Standards. Also, the number of Quality Standards applicable to each service varies depending on the nature of the service provided. Percentage compliance also takes no account of ‘working towards’ a particular Quality Standard. Reviewers often comment that it is better to have a ‘No, but’, where there is real commitment to achieving a particular standard, than a ‘Yes, but’, where a ‘box has been ticked’ but the commitment to implementation is lacking. With these caveats, table 1 summarises the percentage compliance for each of the services reviewed.

Table 1 - Percentage of Quality Standards met

Service	Number of Applicable QS	Number of QS Met	% met
Long-Term Ventilation for Children and Young People			
Long-Term Ventilation Service	77	38	49
University Hospitals of North Midlands NHS Trust	(39)	(25)	(64)
Staffordshire & Stoke on Trent Partnership NHS Trust	(38)	(13)	(34)
Commissioning	4	2	50
Health Economy	81	40	49

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LONG-TERM VENTILATION SERVICE

Ref	Standard: Asterisked sections apply only to children needing level 2/3 care	University Hospitals of North Midlands NHS Trust		Staffordshire & Stoke on Trent Partnership NHS Trust	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
PP-101	<p>Service Information</p> <p>Each service should offer children, young people and families information covering:</p> <ul style="list-style-type: none"> a. What the service provides b. Staff and facilities available c. How to contact the service for help and advice, including 'out of hours' 	Y		N	No information was available for 'c'.

Ref	Standard: Asterisked sections apply only to children needing level 2/3 care	University Hospitals of North Midlands NHS Trust		Staffordshire & Stoke on Trent Partnership NHS Trust	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
PP-102	<p>Information about Long-Term Ventilation</p> <p>Children, young people and families should be offered discussion and access to written information about their long-term ventilation, including:</p> <ul style="list-style-type: none"> a. Description of their condition and its impact b. 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. c. Medication, including what it is for, when to take it, storage and possible side effects d. Management of acute and chronic changes in health e. Lifestyle advice, including nutrition, exercise and travel f. Housing and housing adaptations g. Emotional, spiritual and psychological support for children and young people themselves and for their families, including siblings h. Benefits advice, Personal Health Budgets and how to access charitable and voluntary sector resources i. Transport and mobility j. Other local services available for children and young people with complex care needs and how to access them k. Advance Care Planning (if appropriate) l. Relevant voluntary organisations and support groups m. Where to go for further information, including useful websites 	N	Information for 'c' was not available. Information for 'b' was only available on the intranet. Other information was available in the escalation plan.	N	Information for 'c' was not available and there was only information on equipment ('b') for level three patients. There was information about mobility in the care plan ('i'), but no information about transport.

Ref	Standard: Asterisked sections apply only to children needing level 2/3 care	University Hospitals of North Midlands NHS Trust		Staffordshire & Stoke on Trent Partnership NHS Trust	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
PP-103	<p>Personalised Care Plan</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"> a. Agreed goals b. Care provided by the young person and their family and any training needed c. Continuing care assessment or home care package* d. Therapeutic interventions (pharmacological and non-pharmacological) e. Equipment used and maintenance of equipment f. Contact details for their Home Support Service* g. How to access 24/7 Children's Nursing Support* (QS PP-205) h. Names and contact details for their: <ol style="list-style-type: none"> i. 'Key worker'* (QS PP-105) ii. Community Children's Nurse (QS PP-106) iii. Tertiary Children's LTV Service consultant iv. Community paediatrician i. Choices and options for short breaks* j. Religious, spiritual and cultural needs k. Transport arrangements and transport needs 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 m. Risk assessment n. Planned review date and how to access a review more quickly, if necessary. o. Transition to adult services (if applicable) p. Weaning of ventilation (if applicable) <p>This QS should be met once for each child (not once in each service) and should be communicated to the child's general practitioner.</p>	N	<p>Care plans were in place but they were not always signed. The named nurse did not have any contact details, and families were not clear about whether they had been allocated a named nurse.</p> <p>See main report.</p>	N	<p>Care plans did not include either key worker or community children's nurse details, and were not all signed.</p> <p>There was no transition process identified for young people who did not have a package of care.</p> <p>There was a good risk assessment included, and good photographic evidence for sleep positions.</p> <p>See main report.</p>

Ref	Standard: Asterisked sections apply only to children needing level 2/3 care	University Hospitals of North Midlands NHS Trust		Staffordshire & Stoke on Trent Partnership NHS Trust	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
PP-104	<p>Formal Reviews of Care Plan and Continuing Care Assessment (if applicable)</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> <p>This review should involve, at least:</p> <ol style="list-style-type: none"> The child and their family Their 'key worker'* (QS PP-105), Community Children's Nurse (QS PP-106), Tertiary Children's LTV Service consultant, community paediatrician, social care* and education* representative Any other staff with regular input to the care of the child Any other consultants with regular input to the care of the child <p>The review should cover all aspects of the Personal Care Plan (QS PP-103). The young person and their family should be offered any relevant additional information (QS PP-102) and their Personal Care Plan should be updated. The outcome of the review should be communicated to the relevant commissioner of care and to the child's general practitioner.</p> <p>This QS should be met once for each child (not once in each service).</p>	N	<p>A multi-disciplinary review was in place but did not include all staff identified in the Quality Standard.</p> <p>See main report.</p>	N	<p>Reviews did not include all staff named in the Quality Standard. The service may wish to consider closer joint working with the UHNM service.</p> <p>See main report.</p>

Ref	Standard: Asterisked sections apply only to children needing level 2/3 care	University Hospitals of North Midlands NHS Trust		Staffordshire & Stoke on Trent Partnership NHS Trust	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
PP-105	<p>‘Key Worker’ (Level 2/3 only)</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"> Maintaining regular contact with the child and their family and providing information, support and advice covering all aspects of Qs PP-103 Liaison with the child’s named Community Children’s Nurse (if a different person) Keeping relevant documentation up to date, including the Personal Care Plan, Agreement of Care, Education Health Care Plan and related risk assessments Informing other services involved with the child about changes to their condition or plan of care (QS PP-103) Informing the child’s school of changes to their condition or plan of care (QS PP-103) 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 PP-104) Initiating and / or participating in multi-disciplinary discharge planning (QS PP-602) Initiating and updating the child’s Common Assessment Framework (if applicable) Consideration of and acting on safeguarding issues <p>This QS should be met once for each child (not once in each service).</p>	N	Key workers were not yet in place.	N	Key workers were not yet in place. Families were not able to identify a specific member of staff responsible for advice, queries and support.

Ref	Standard: Asterisked sections apply only to children needing level 2/3 care	University Hospitals of North Midlands NHS Trust		Staffordshire & Stoke on Trent Partnership NHS Trust	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
PP-106	<p>Community Children's Nurse</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 (not once in each service).</p>	N	Some children did not have an identified community children's nurse. University Hospitals of North Midlands did not consider that it was commissioned to meet this Quality Standard.	N	Some children did not have an identified community children's nurse.
PP-107	<p>Agreement of Care (Level 2/3 only)</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>	N/A	The service did not provide any home-based care.	Y	

Ref	Standard: Asterisked sections apply only to children needing level 2/3 care	University Hospitals of North Midlands NHS Trust		Staffordshire & Stoke on Trent Partnership NHS Trust	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
PP-108	<p>Education Health Care Plan</p> <p>Each child should have an Education Health Care Plan covering at least:</p> <ul style="list-style-type: none"> a. School attended b. Transport to and from school* c. Care required while at school* d. Responsibilities of carers and of school staff e. Training and competency requirements for whoever is providing the child's care in school* f. Likely problems and what to do if these occur g. What to do in an emergency (or a copy of the child's Emergency Health Care Plan) h. Arrangements for liaison with the school i. Review date and review arrangements 	N	Education health care plans were not yet in place. University Hospitals of North Midlands did not consider that it was commissioned to meet this Quality Standard.	N	Education health care plans were not yet in place.
PP-109	<p>Self-Care and Family Involvement in Care</p> <p>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 update as necessary.</p>	Y		Y	

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		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
PP-110	<p>Facilities for Families</p> <p>Services providing overnight care away from the child's home should have:</p> <ul style="list-style-type: none"> a. Information for families on service routines, facilities that families may want to use, transport facilities and car parking b. Appropriate facilities for families, including for other children 	Y	Good facilities were available.	N/A	
PP-111	<p>Play and Psychological Support</p> <p>Children and young people and their families should have direct access to the following:</p> <ul style="list-style-type: none"> a. Play support to enable the child's development and well-being b. Play and distraction during any painful or invasive procedures c. Psychological support for the child, parents, siblings and other close family members d. An assessment of the needs of family carers e. Information and advice on services available to provide support to siblings and family members 	Y		N	Play support was not available.

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		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
PP-196	<p>General Support for Children and their Families</p> <p>Each child and their family should have easy access to the following services. Information about these services should be easily available:</p> <ul style="list-style-type: none"> a. Interpreter services b. PALS and how to make a comment, compliment or complaint c. Spiritual support d. HealthWatch or equivalent organisation 	Y		N	Information for 'c' and 'd' was not available.
PP-199	<p>Involving Children, Young People and Families</p> <p>The service should have:</p> <ul style="list-style-type: none"> a. Mechanisms for receiving feedback from children, young people and their families about the treatment and care they received. b. Mechanisms for involving children, young people and families in decisions about the organisation of the service. c. Examples of changes made as a result of feedback and involvement of children, young people and their families. 	Y		N	Mechanisms were in place for patients to give feedback to the service, but it was not clear if any changes had been made as a result of patient feedback.

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		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
PP-201	<p>Clinical Leadership</p> <p>The service should have the following nominated clinical leads:</p> <p>a. Lead nurse or other registered healthcare professional with:</p> <p>i. Training and experience in the care of children on long-term ventilation</p> <p>ii. Competences in management and leadership</p> <p>b. Lead paediatric respiratory or intensive care consultant (Tertiary Children's LTV Services only)</p> <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>	Y	<p>Clinical leadership from a 0.6 w.t.e. lead nurse and a paediatric respiratory consultant with allocated time in his/her job plan were in place for the service.</p> <p>See main report.</p>	N	<p>There was no clear clinical leadership for the service. Two case managers with experience in the care of children on long-term ventilation and a non-clinical manager were in place.</p> <p>See main report.</p>

Ref	Standard: Asterisked sections apply only to children needing level 2/3 care	University Hospitals of North Midlands NHS Trust		Staffordshire & Stoke on Trent Partnership NHS Trust	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
PP-202	<p>Staffing Levels – Tertiary Children’s LTV Services</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"> Medical staff Nursing staff with a minimum of 75% children’s trained nurses Children’s carers, all of whom should have a NVQ level 3 in a child or young adult-related subject (or equivalent) Physiotherapy (Monday to Friday and on call at weekends) Occupational therapy (Monday to Friday) Dietetics (Monday to Friday) Speech and language therapy (Monday to Friday) Clinical and educational psychological support (Monday to Friday) Play support (Daily) Youth workers (Flexible availability depending on the needs of the child) <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>	N	<p>There was no cover for the clinical nurse specialist at the time of the visit. Recruitment was, however, underway and the issue was expected to be addressed shortly after the visit. Support therapists did not have designated time for the service but were available Monday to Friday. Cover for medical staff was not clear. Youth workers were not available (‘j’).</p> <p>See main report.</p>	N/A	

Ref	Standard: Asterisked sections apply only to children needing level 2/3 care	University Hospitals of North Midlands NHS Trust		Staffordshire & Stoke on Trent Partnership NHS Trust	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
PP-203	<p>Staffing Levels – Home Support and ‘Step Down / Short Break’ Services</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> <ul style="list-style-type: none"> 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 NVQ level 3 in a child or young adult-related subject (or equivalent) <p>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 PP-105), nominated Community Children’s Nurse (QS PP-106) 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.</p>	N/A		Y	

Ref	Standard: Asterisked sections apply only to children needing level 2/3 care	University Hospitals of North Midlands NHS Trust		Staffordshire & Stoke on Trent Partnership NHS Trust	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
PP-204	<p>Competence Framework and Training Plan</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"> Ventilation Resuscitation Transporting ventilated children* Professional boundaries Child safeguarding Working in the home environment* (where applicable) Infection control and disposal of clinical waste <p>Where appropriate for the needs of the child:</p> <ol style="list-style-type: none"> Tracheostomy care* Oxygen via a ventilator Humidification* Saturation monitoring Urinary catheterisation* Spinal care* Nasogastric feeding or gastrostomy* <p>A competence framework should show the competences expected for different roles within the service and a training plan should cover achievement and maintenance of these competences.</p>	N	<p>Competences were only available for tracheostomy ('h'). The Trust mandatory training and the service training matrix covered 'b', 'e' and 'g' but not the other aspects of the Quality Standard.</p> <p>See main report.</p>	N	<p>Competences for 'b', 'd', 'e' and 'f' were not identified. There was information about evacuation from the home. No competence framework or training plan was in place.</p> <p>See main report.</p>

Ref	Standard: Asterisked sections apply only to children needing level 2/3 care	University Hospitals of North Midlands NHS Trust		Staffordshire & Stoke on Trent Partnership NHS Trust	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
PP-205	<p>24/7 Children's Nursing Support (Level 2/3 only)</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"> Have access to each child's latest Personal Care Plan (QS PP-103) Have information about the equipment used and maintenance arrangements Have access to the child's Tertiary Children's LTV Service for advice (QS PP-207) <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>	N/A		N	It was not clear how 24/7 nursing support was organised to give continuity of care.
PP-206	<p>Observation of Practice</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>	N/A		N	Observation of practice had commenced but there was no record of how much had been carried out.

Ref	Standard: Asterisked sections apply only to children needing level 2/3 care	University Hospitals of North Midlands NHS Trust		Staffordshire & Stoke on Trent Partnership NHS Trust	
		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
PP-207	<p>Tertiary LTV Advice Service</p> <p>The following staff should be available at all times(24/7) to provide advice to services with the network:</p> <ul style="list-style-type: none"> a. Paediatric respiratory or intensive care consultant b. Registered children’s nurse with competences in the care of children needing long-term ventilation 	Y		N/A	
PP-208	<p>Emotional Support for Staff</p> <p>All staff should have direct access to emotional and psychological support or counselling.</p>	Y		Y	
PP-209	<p>Clinical Supervision</p> <p>All healthcare professionals should be offered regular clinical supervision appropriate to their role at least quarterly. This should include ‘safeguarding supervision’</p>	Y		N	A policy was in place, but it was not clear if all staff were offered regular clinical supervision.
PP-299	<p>Administrative and Clerical Support</p> <p>Administrative, clerical and data collection support should be appropriate for the number of children cared for by the service.</p>	Y	Some administrative support was available, and further support had been requested as part of a wider business case that was under consideration.	N	No administrative support was available. A post was being advertised at the time of the review.

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		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
PP-301	<p>Support Services – Home Support and ‘Step Down / Short Break’ Services</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"> Physiotherapy (Monday to Friday) Occupational therapy (Monday to Friday) Dietetics (Monday to Friday) Speech and language therapy (Monday to Friday) Clinical and educational psychological support (Monday to Friday) Play support (Daily) Youth workers (Flexible availability depending on the needs of the child) <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>	Y	It was not clear that all young people could access a youth worker.	Y	It was not clear that all young people could access a youth worker.

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PP-302	<p>Other Services Providing Support Where Care is Delivered</p> <p>The following services should be available to support children on long-term ventilation in the location where care is delivered:</p> <ul style="list-style-type: none"> a. Education services (Monday to Friday) b. Chaplain or multi-faith representative (24/7) c. Home Oxygen Assessment and Review Service (7/7) d. Transport services for children with complex needs* (Monday to Friday) e. Social work (Monday to Friday) and Emergency Duty Team 	N	Home oxygen assessment ('c') was available Monday to Friday only. Transport ('d') was reported as problematic for children in wheelchairs, although transport arranged through Treetops Hospice was good.	N	Transport services ('d') were difficult to access.
PP-303	<p>Other Support Services</p> <p>Timely access to the following services should be available:</p> <ul style="list-style-type: none"> a. Pharmacy advice (telephone advice 7/7) b. Respiratory physiology, lung function tests and sleep studies c. Wheelchair assessment, supply and maintenance service (if required) d. Assessments for housing adaptations* e. Community paediatrician f. Continence services (if required) 	Y	There were delays of up to six months for sleep studies ('b').	Y	

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		Met? Y/N	Reviewer Comments	Met? Y/N	Reviewer Comments
PP-304	<p>Support Services – Tertiary Children’s LTV Services</p> <p>Tertiary long-term ventilation services should be based on the same hospital site as:</p> <p>a. 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 4th Edition (2010).</p> <p>b. Consultant-led ENT service.</p>	Y		N/A	

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PP-401	<p>Equipment Timely access to the following equipment should be available:</p> <p>Each child who is ventilator dependent (level 2 or 3):</p> <ul style="list-style-type: none"> a. Two ventilators including internal and external battery backup b. Two oxygen saturation monitor or one oxygen saturation monitor and robust arrangements for replacement within 12 hours c. Hand-held saturation monitor d. Self inflating bag e. Two sets of suction equipment f. Two sets of appropriate humidification equipment g. Access to a mobile phone and to a land line in the home (or back up mobile) h. Equipment needed for tracheotomy care i. Height adjustable (profiling) bed or cot j. Back up lighting k. Call system l. Adequate seating for care staff m. Dimmable background lighting n. Adequate number of electrical points o. Supply of consumables p. Appropriate storage for equipment and consumables q. If required: <ul style="list-style-type: none"> i. Sleep system ii. Communication aids iii. Feed pump iv. Physiotherapy equipment v. Wheelchair vi. Nebuliser vii. Carbon dioxide monitoring equipment viii. Chest physiotherapy equipment <p>Each child needing level 1 ventilatory support:</p> <ul style="list-style-type: none"> r. One ventilator in the home s. Access to a replacement ventilator within 24 hours <p>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.</p>	Y		N	There were delays in accessing equipment and consumables. This was under discussion with the commissioners at the time of the visit.

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PP-501	<p>Guidelines on Initiation of Ventilation</p> <p>Guidelines on initiation of ventilation should be in use covering at least:</p> <ul style="list-style-type: none"> a. Involvement of the family and consent for initiation of long-term ventilation b. Multi-disciplinary discussion involving staff of the Tertiary Children's LTV Service* 	Y		N/A	
PP-502	<p>Clinical Guidelines</p> <p>Clinical guidelines should be in use covering common problems in the care of children on long-term ventilation, including:</p> <ul style="list-style-type: none"> a. Pressure sores and tissue viability b. Tracheostomy care* c. Ventilation d. Suction of natural and artificial airways* e. Oxygen therapy f. Saturation monitoring g. Resuscitation h. Gastrostomy* i. Venous thrombo-embolism assessment and prevention* 	Y		Y	

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PP-601	<p>Operational Policy</p> <p>The service should have an operational policy covering, at least:</p> <ol style="list-style-type: none"> a. Criteria and arrangements for referral into the service b. Handover to and from 24/7 Children's Nursing Support (QS PP-205) and ensuring all appropriate information is available c. Documentation of Personal Care Plan and Care Package in the Personal Care Record (QS PP-103) d. Agreement and documentation of all relevant assessments and plans (note 3) e. Confirmation of the child's: <ol style="list-style-type: none"> i. 'Key worker'* (QS PP-105) ii. Community Children's Nurse (QS PP-106) iii. Tertiary Children's LTV Service consultant iv. Community paediatrician f. Communication of any changes to the plan of care to the: <ol style="list-style-type: none"> i. Local acute Trust to which the child is usually admitted for acute exacerbations ii. Child's school and, if necessary, changing their Education Health Care Plan g. Consideration of and acting on safeguarding issues h. Indications and arrangements for accessing the Tertiary LTV Advice Service (QS PY-604) i. Arrangements for professional carers to work in other settings, such as the 'Step Down' service or local acute hospital*: <ol style="list-style-type: none"> i. For training ii. To provide care for the child during a short break or hospital stay j. System for support for staff (QS PP-208) k. Discharge to the care of 'universal' children's services or specialist disability services l. Criteria and arrangements for referral to children's palliative care services 	Y		N	A draft policy was in place. This was due to be finalised when the new service specification was in place.

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PP-602	<p>Discharge Guidelines</p> <p>Network-agreed guidelines for discharge from hospital (QS PY-602) should be in use.</p>	N/A		N/A	
PP-603	<p>Multi-Agency Care Planning Policy</p> <p>A policy covering multi-agency care planning and continuing care assessment should be in use covering all aspects of QS PP-103 and involving:</p> <ol style="list-style-type: none"> The child themselves and their family The child's general practitioner The child's 'key worker'*, community children's nurse, Tertiary Children's LTV Service consultant and community paediatrician All relevant staff from the service (QS PP-203) Representatives of other services involved in the care of the child Social work, education and relevant voluntary service representatives <p>Links with Children's Assessment Framework processes and the 'Team around the Child' should be clear.</p>	Y		N	No policy was in place.
PP-604	<p>Weekly Review (Level 2/3 only)</p> <p>A registered health care professional with competences in the care of children needing long-term ventilation should visit the child and family at least weekly to monitor their well-being and the adequacy of care arrangements. There should be reasonable continuity of staff undertaking the weekly review.</p>	N	Arrangements for weekly review were not yet in place.	N	Arrangements for weekly review were not yet in place.

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PP-605	<p>Guidelines on Communication with Ambulance Service</p> <p>The ambulance service should be informed of:</p> <ul style="list-style-type: none"> 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 b. When the child of young person is no longer at a residential address. 	Y		Y	
PP-606	<p>Equipment Policy</p> <p>An Equipment Policy should be in use covering responsibilities and arrangements for:</p> <ul style="list-style-type: none"> a. Setting up equipment b. Maintenance and servicing of equipment c. Emergency replacements d. Replacement of breakages e. Emergency contact details f. Return of equipment when no longer needed 	Y		Y	The policy was under review.
PP-607	<p>Equipment Register</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>	Y		Y	

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PP-608	<p>Transition Guidelines</p> <p>Guidelines on transition should be in use, covering:</p> <ol style="list-style-type: none"> Age guidelines for timing of transition Involvement of the young person and their family in the decision about transition Multi-disciplinary planning of the transition with primary health care, social care, education service and adult services Joint meetings with the young person, their family and children's and adult services prior to transition Responsibility for key working functions during the transition period A preparation period and education programme relating to transition Arrangements for monitoring during the time immediately after transition 	N	<p>Guidelines were available but were not fully implemented. A business case to support implementation was under development. Patients and carers were not clear about the transition process.</p> <p>See main report.</p>	N	<p>A transition pathway was in place for patients with a continuing healthcare package. There was no clear process for level 3 patients. Patients and carers were not clear about the transition process.</p> <p>See main report.</p>
PP-609	<p>Liaison with Support Services</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"> Special Educational Needs services Transport services* Equipment supply and maintenance services Acute Trusts to which children are normally admitted with acute exacerbations (if not the Tertiary Children's LTV Service) 	Y		Y	

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PP-610	<p>Children's Long-Term Ventilation Network</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>	Y		Y	
PP-701	<p>Data Collection</p> <p>There should be regular collection of data and monitoring of:</p> <ul style="list-style-type: none"> a. Number of children cared for by the service b. Number of staff involved in each care package* c. Percentage of shifts not covered* (excluding shifts cancelled by parents or due to admission of children to hospital) d. Proportion of face to face contact time provided by registered health care professionals* e. Achievement of weekly review visits* (QS PP-604) f. Frequency of observation of practice for all children's carers* (QS PP-206) g. Calls to the 24/7 Children's Nursing Support (QS PP-205) outside normal working hours* h. Achievement of expected timescales for discharge (QS PY-602) i. Reporting of required data to the Central LTV Pathway Team* j. Other key performance indicators agreed by the National Service Specification* or Children's Long-Term Ventilation Network 	N	<p>Data were not collected.</p> <p>See main report.</p>	N	<p>Data were not collected.</p> <p>See main report.</p>

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PP-702	<p>Audit</p> <p>The services should have a rolling programme of audit, including audit of:</p> <ul style="list-style-type: none"> a. Completeness of the Personal Care Plan (QS PP-103) and whether reviewed at least annually (QS PP-104) b. Compliance with clinical guidelines (QS PP-501 and PP-502) c. PAT Testing and Equipment Service and Maintenance 	N	<p>Audits did not include 'a' or 'b'.</p> <p>See main report.</p>	N	<p>A rolling programme of audit was not in place.</p> <p>See main report.</p>
PP-798	<p>Review and Learning</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>	Y		Y	
PP-799	<p>Document Control</p> <p>All policies, procedures and guidelines should comply with Trust or employing organisation's document control procedures.</p>	N	<p>Document control was not evident for service level documents.</p>	N	<p>Document control was not evident for all documents.</p>

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COMMISSIONING

Ref	Standard	Met? Y/N	Reviewer Comments
PZ-603	<p>Commissioning: Long-Term Ventilation for Children and Young People</p> <p>Services to meet the needs of children and young people on long-term ventilation should be commissioned, including:</p> <ol style="list-style-type: none"> Tertiary Children’s LTV Service ‘Step-Down / Short Break’ Service Home Support Service/s Regional Children’s LTV Network <p>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.</p>	Y	
PZ-604	<p>Discharge Planning Guidelines</p> <p>Commissioners should agree the Children’s Long-Term Ventilation Network guidelines on discharge from hospital (QS PY-602).</p>	N	Commissioners had not yet agreed the guidelines that were available at the time of the review.
PZ-605	<p>Education of Children and Young People on Long-Term Ventilation (Level 2/3 only)</p> <p>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:</p> <ol style="list-style-type: none"> Arrangements for liaison with schools and colleges Agreement of an Education Health Care Plan for each child (QS PP-108) Visits to the school by relevant staff to discuss the care of each child starting long-term ventilation Responsibilities of school staff in the care of the child Training and assessment of competences of school staff in these responsibilities Disposal of clinical waste (if applicable) 	Y	The joint commissioning strategy was comprehensive.
PZ-701	<p>Quality Monitoring: Children’s Long-Term Ventilation Services</p> <p>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.</p>	N	Data were not collected for the service (QS PP-701). Some Key Performance Indicators were collected and monitored.

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