

Long-Term Ventilation for Children and Young People

Children and Young People's Palliative Care

Worcestershire Health and Care NHS Trust in partnership with
Worcester Acute Hospitals NHS Trust

Visit Date: 26th March 2014

Report Date: July 2014



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INTRODUCTION

This report presents the findings of the review of Children and Young People's Palliative Care and Services Providing Long-Term Ventilation for Children and Young People which took place on 26th March 2014. The purpose of the visit was to review compliance with West Midlands Quality Review Service (WMQRS) Quality Standards for:

- Children and Young People's Palliative Care in the West Midlands, Version 1, November 2012
- Long-Term Ventilation for Children and Young People, Version 2, December 2013

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 which reviewed the services at Worcester Health and Care NHS Trust. 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 Joint Commissioning Unit within Worcestershire County Council through collaboration with South Worcestershire, Wyre Forrest and Redditch and Bromsgrove Clinical Commissioning Groups.

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 the Joint Commissioning Unit within Worcestershire County Council.

ABOUT WEST MIDLANDS QUALITY REVIEW SERVICE

WMQRS was set up as a collaborative venture by 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.wmqrns.nhs.uk

ACKNOWLEDGMENTS

West Midlands Quality Review Service would like to thank the staff and service users and carers in Worcestershire 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

LONG-TERM VENTILATION SERVICE (WORCESTERSHIRE HEALTH AND CARE TRUST)

The service was provided by Worcestershire Health and Care NHS Trust in partnership with Worcester Acute Hospitals NHS Trust as part of the 'Orchard Service'. Care of children requiring long-term ventilation, provided through a Home Support Team, was commissioned on a named child basis following a Continuing Health Care assessment and application for individual funding. These children also had access to other elements of the Orchard Service. In addition to the commissioned care package, the Orchard Service provided support training and management by registered health care professionals until 8pm. An on call service was available for children on long-term ventilation at all times.

At the time of the review the service cared for eight children requiring long-term ventilation.

General Comments and Achievements

The specialist long-term ventilation team provided a well-managed, robust and sustainable service. Clinical leadership of the team was strong. Relationships with the Acorns Hospice and with the tertiary long-term ventilation service were working well. The Worcestershire service was well-respected and other services had confidence in the care provided. Staff were highly dedicated and prepared to go above and beyond the normal expectation for their roles.

Immediate Risks: No immediate risks were identified.

Concerns

1 Competence Framework

The competence framework in use by the team was not the latest version and some sections had not yet been completed.

2 Review of Continuing Care Assessments

Continuing care assessments were not being reviewed. As a result, the agreed packages may no longer be meeting the child and family's needs.

3 Competence Assessment of Night-time Carers

Carers working in the home at night were being signed off as competent without nursing staff having seen them performing the expected competences in the home environment. This issue had, however, been recognised and revised arrangements were being introduced.

Further Consideration

1 The on-line version of the national competences has been available since 2010 and these competences are regularly updated. Reviewers suggested that the on-line version should be used as a matter of routine.

2 No representatives of the service had attended the regional long-term ventilation network for about 18 months. As a result, staff may not be fully aware of latest developments in the care of children needing long-term ventilation (as illustrated by the use of an out of date competence framework).

3 The service did not have access to local community-based respiratory physiotherapy. Children needing respiratory physiotherapy accessed the Worcestershire-based hospital service or the respiratory outreach service from Birmingham Children's Hospital. Both options were not ideal from the family's perspective and may not represent the best use of NHS resources. Also, there was no ongoing input to multi-disciplinary discussion about the child's care from a respiratory physiotherapist. Reviewers suggested that

allocating some respiratory physiotherapist time to work with the service would improve the service offered and may be a better use of NHS resources.

- 4 The service did not have access to community-based dietetic advice. This is particularly important for children on long-term ventilation and would improve the quality of the service offered.
- 5 Little information was available on how families could access help with transport.
- 6 The IT available to the service did not support staff working in patients' homes, including electronic access to the latest care plans and to relevant lists, including equipment lists which could be needed in an emergency.
- 7 Several of the policies were awaiting ratification and some policies had not yet been developed. It will be important to ensure that the programme of policy development and approval is completed.

ACUTE HOSPITAL CARE

Concerns

1 Acute Hospital Admission of Children on Long-Term Ventilation

Children with tracheostomies, on CPAP, non-invasive ventilation or invasive ventilation were not admitted to the paediatric ward at Worcestershire Royal Hospital, even if they were stable from a respiratory perspective. These children therefore had to be admitted to either Birmingham Children's Hospital or Stoke which was inconvenient for families and used capacity which may be required for other children at greater need. The paediatric ward at Worcestershire Royal Hospital appeared to have capacity available, staff with appropriate competences were available because acute CPAP was provided and community-based nurses were prepared to provide additional support during admission of these children. Reviewers were unclear why admission to Worcestershire Royal Hospital was not part of the local care pathway.

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CHILDREN AND YOUNG PEOPLE'S PALLIATIVE CARE

PAEDIATRIC PALLIATIVE CARE SERVICE (WORCESTERSHIRE HEALTH AND CARE TRUST)

The paediatric palliative care team was also part of the Orchard Service. Established in 2004 and expanded since then, this team provided 24 hour support, advice and care for children and young people nearing the end of life. The service comprised a multi-disciplinary team, including specialist nurses, play specialists, psychological support and a social worker.

At the time of the review the service cared for 176 children requiring palliative care.

General Comments and Achievements

The palliative care team provided a very good service for children with life-limiting conditions. The service was well-respected and trusted by parents, families and other services. Reviewers were impressed to see a psychologist, social worker and play specialist with time allocated for their work within the team. Clinical leadership of the team was strong. Multi-disciplinary care planning was good and included very good joint work with social care, education and Acorns Hospice. Staff were highly dedicated and prepared to go above and beyond the normal expectation for their roles.

Good Practice

- 1 Good child-friendly, age appropriate information about conditions was available and included good use of pictures and other visual images.

- 2 The service had good access to equipment with a quick response time, including at night. Reviewers were impressed that funding decisions did not delay supply of equipment.
- 3 An innovative programme of embedding social workers for children with disabilities within special schools was being developed. Health, education and social care staff were based together in the special school and 'out-reached' to other children in mainstream schools.

Immediate Risks: No immediate risks were identified

Concerns

1 Medical Staffing

In practice, the service had no sessional input from a consultant paediatrician. Reviewers were told that one paediatrician had one session per week in their job plan for leading the service but other members of the team were not aware of this and the paediatrician had no clinical involvement with the team. Nursing staff therefore approached different community or acute paediatricians, or other consultants from around the region, when advice was needed.

2 Key Working

'Key working' principles were generally followed but were not firmly embedded into the organisation of the service. Information for families and patients' notes did not include the 'key worker' and parents who met the visiting team were not aware of their 'key worker'.

Further Consideration

- 1 Nurse staffing levels were low for the number of patients. Better collaboration and flexibility between acute and community nursing teams could help to address this issue (see below). Evidence of palliative care-related competences was limited although reviewers were given verbal information on this. A more robust approach to documenting competences expected and achieved would help to ensure all staff have and are maintaining appropriate competences.
- 2 Reviewers suggested that improved links between acute and community nursing teams could help to improve care for children in both sectors. Reviewers saw no evidence of joint training, shared protocols or flexible staffing arrangements.
- 3 The palliative care team had good, child-friendly documentation on diagnosis and changes in prognosis. It was not clear how the team worked with medical and nursing staff at Worcestershire Royal Hospital at these times and whether everyone who was involved with the care of children or young people was using the same documentation.
- 4 Children and young people's wishes for their life and care were not reflected in any of the documentation and reviewers suggested that a 'child's wishes' section in all documentation may be helpful. Reviewers also suggested that the team agree and document clearly what families are expected to do. Empowering families actively to be involved in their child's care did not come out strongly in the information for families and other documentation.
- 5 Feedback from families who met the team was that they would have liked greater clarity at an earlier stage about how much support they would get after a bereavement and when this would stop.
- 6 Reviewers heard from several sources that links with community paediatricians in the Redditch area were not as strong as those in other parts of Worcestershire. The service should ensure that any problems are identified and addressed.
- 7 Several of the policies were awaiting ratification and some policies had not yet been developed. It will be important to ensure that the programme of policy development and approval is completed.

- 8 Formal arrangements for access to additional carers at short notice, for example, to get children home quickly or to cover unexpected staff absences, should be considered. This could be achieved through a link with a larger service and / or through improved links with Worcestershire Acute Hospitals NHS Trust.

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ACUTE HOSPITAL CARE

Riverbank Ward at Worcestershire Royal Hospital was well laid out and spacious and provided a good environment for children needing acute hospital admission.

Concerns

- 1 **Acute Hospital Admission for Children with Tracheostomies or Needing Ventilation**

See long-term ventilation section of this report.

- 2 **Toilet Facilities for Parents**

Toilet facilities for parents of children who were admitted to Riverbank Ward at Worcestershire Royal Hospital were within the parent's bedroom. The parent's bedroom did not lock and no other toilet for parents was available on the ward. This did not provide appropriate security for parents who were staying overnight. Also, if the bedroom was in use then other parents were directed by staff to use the staff toilet.

Further Consideration

- 1 Reviewers suggested that improved links between acute and community nursing teams could help to improve care for children in both sectors. Reviewers saw no evidence of joint training, shared protocols or flexible staffing arrangements.
- 2 See also 'Service Providing Paediatric Palliative Care' (above), Further Consideration points 1 and 3.

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COMMISSIONING

Immediate Risks: No immediate risks were identified

Concerns

- 1 **Acute Hospital Admission for Children with Tracheostomies or Needing Ventilation:** See long-term ventilation section of this report.

- 2 **Review of Continuing Care Assessments**

Continuing care assessments were not being reviewed. As a result, the agreed packages may no longer be meeting the child and family's needs.

- 3 **Service Specification**

Service specifications were not available for either of the services reviewed and key performance indicators did not appear to be being monitored routinely. Service specifications for both services are available from regional networks, including key performance indicators for long-term ventilation services. Reviewers suggested that the service commissioners use the specifications, especially to support discussions with the acute Trust.

4 Other Issues

The following issues were also identified as concerns and commissioner involvement in their resolution may be required:

- a. **Long-Term Ventilation Service:**
 - i. Competence Framework
 - ii. Competence Assessment of Night-time Carers
- b. **Paediatric Palliative Care Service**
 - i. Medical Staffing
 - ii. Key Working

Further Consideration

- 1 Birmingham Children's Hospital NHS Foundation Trust was being used to provide support for acute admissions, respiratory physiotherapy and dietetics which could be provided within Worcestershire. These arrangements did not provide good access for the child and their family and used capacity which may be required for other children at greater need.
- 2 Reviewers were told about several changes of commissioning staff. Reviewers suggested that commissioners should ensure they are clear about their responsibilities and those of NHS England specialised services commissioners. One example of this was that the GP admission avoidance pilot appeared to be providing some care for children on long-term ventilation and those with palliative care needs which was the responsibility of NHS England.

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APPENDIX 1 MEMBERSHIP OF VISITING TEAM

Reviewers

Wendy Godwin	Lead Commissioner Planned Care	NHS Walsall Clinical Commissioning Group
Joanne Holder	Clinical Lead, Children's Community Nursing Team	South Warwickshire NHS Foundation Trust
Dr Pavanasam Ramesh	Consultant in PICU and General Paediatrics	University Hospital of North Staffordshire NHS Trust
Dr Claire Thomas (Lead)	Consultant Paediatrician	The Royal Wolverhampton NHS Trust
Joanne Watson	Deputy Head of Nursing and Service Manager	Birmingham Children's Hospital NHS Foundation Trust
Abbie Wood	Sister, Paediatrics	The Royal Wolverhampton NHS Trust

Observer

Julie Newton	Support Officer - Children's Division	Black Country Partnership NHS Foundation Trust
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WMQRS Team

Jane Eminson	Acting 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 varied 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 & Young People Children and Young People's Palliative Care			
Long-Term Ventilation Service	39	22	56
Palliative Care for Children & Young People	41	33	80
Commissioning – Long-term Ventilation Service	4	2	50
Commissioning – Palliative Care for Children & Young People	5	1	20

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LONG-TERM VENTILATION SERVICE

Ref	Standard: Asterisked sections apply only to children needing level 2/3 care	Met?	Comment
PP-101	<p>Service Information</p> <p>Each service should offer children, young people and families information covering:</p> <ol style="list-style-type: none"> What the service provides Staff and facilities available How to contact the service for help and advice, including 'out of hours' 	Y	Service information was available although not all the parents who reviewers met had seen it. The document stated that the information was for 'technology dependent children' and reviewers suggested that the terminology be changed to children receiving 'long-term ventilation'.
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> <ol style="list-style-type: none"> Description of their condition and its impact 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. Medication, including what it is for, when to take it, storage and possible side effects Management of acute and chronic changes in health Lifestyle advice, including nutrition, exercise and travel Housing and housing adaptations Emotional, spiritual and psychological support for children and young people themselves and for their families, including siblings Benefits advice and how to access charitable funding and other resources Transport and mobility Other local services available for children and young people with complex care needs and how to access them Advance Care Planning (if appropriate) Relevant voluntary organisations and support groups Where to go for further information, including useful websites 	N	This Quality Standard was almost met and the service had an action plan in place to identify and rectify any gaps.

Ref	Standard: Asterisked sections apply only to children needing level 2/3 care	Met?	Comment
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> <ul 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: <ul 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>	Y	<p>There was no documented information about a ‘key worker’ but in practice this appeared to be in place. Some parents were not aware of their key worker. See Quality Standard PP-105.</p>

Ref	Standard: Asterisked sections apply only to children needing level 2/3 care	Met?	Comment
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"> a. The child and their family b. 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 c. Any other staff with regular input to the care of the child d. 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>There was no review of continuing care assessments and therefore packages of care may be inappropriate and may not be responsive to the needs of either families or the service. See main report.</p>

Ref	Standard: Asterisked sections apply only to children needing level 2/3 care	Met?	Comment
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> <ul style="list-style-type: none"> a. Maintaining regular contact with the child and their family and providing information, support and advice covering all aspects of Qs PP-103 b. Liaison with the child's named Community Children's Nurse (if a different person) c. Keeping relevant documentation up to date, including the Personal Care Plan, Agreement of Care, School Health Care Plan and related risk assessments d. Informing other services involved with the child about changes to their condition or plan of care (QS PP-103) e. Informing the child's school of changes to their condition or plan of care (QS PP-103) f. 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) g. Initiating and / or participating in multi-disciplinary discharge planning (QS PP-602) h. Initiating and updating the child's Common Assessment Framework (if applicable) i. Consideration of and acting on safeguarding issues <p>This QS should be met once for each child (not once in each service).</p>	N	This process was not formalised or embedded into working practices and it was not reflected in documented evidence. Some parents did not know who their key worker was.
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>	Y	
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>	Y	Care agreements were in place but they were not personalised and there was nowhere to sign to indicate agreement. Reviewers suggested further personalisation of the agreements and the inclusion of a space for signatures.

Ref	Standard: Asterisked sections apply only to children needing level 2/3 care	Met?	Comment
PP-108	<p>School Health Care Plan</p> <p>Each child should have an School Health Care Plan covering at least:</p> <ol style="list-style-type: none"> School attended Transport to and from school* Care required while at school* Responsibilities of carers and of school staff Training and competency requirements for whoever is providing the child's care in school* Likely problems and what to do if these occur What to do in an emergency (or a copy of the child's Emergency Health Care Plan) Arrangements for liaison with the school Review date and review arrangements 	N	The service only cared for one school age child.
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>	N	Competences for parents were not formally re-assessed annually. Parents said they were well supported when they had to demonstrate competences.
PP-110	<p>Facilities for Families</p> <p>Services providing overnight care away from the child's home should have:</p> <ol style="list-style-type: none"> Information for families on service routines, facilities that families may want to use, transport facilities and car parking Appropriate facilities for families, including for other children 	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> <ol style="list-style-type: none"> Play support to enable the child's development and well-being Play and distraction during any painful or invasive procedures Psychological support for the child, parents, siblings and other close family members An assessment of the needs of family carers Information and advice on services available to provide support to siblings and family members 	Y	

Ref	Standard: Asterisked sections apply only to children needing level 2/3 care	Met?	Comment
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	
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	Children, young people and their families were included in decisions about the service wherever possible.
PP-201	<p>Clinical Leadership</p> <p>The service should have the following nominated clinical leads:</p> <ul style="list-style-type: none"> a. Lead nurse or other registered healthcare professional with: <ul style="list-style-type: none"> i. Training and experience in the care of children on long-term ventilation ii. Competences in management and leadership b. Lead paediatric respiratory or intensive care consultant (Tertiary Children's LTV Services only) <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	

Ref	Standard: Asterisked sections apply only to children needing level 2/3 care	Met?	Comment
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> <ul style="list-style-type: none"> a. Medical staff b. Nursing staff with a minimum of 75% children’s trained nurses c. Children’s carers, all of whom should have a NVQ level 3 in a child or young adult-related subject (or equivalent) d. Physiotherapy (Monday to Friday and on call at weekends) e. Occupational therapy (Monday to Friday) f. Dietetics (Monday to Friday) g. Speech and language therapy (Monday to Friday) h. Psychological support (Monday to Friday) i. Play support (Daily) j. 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/A	

Ref	Standard: Asterisked sections apply only to children needing level 2/3 care	Met?	Comment
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. Nursing staff with a minimum of 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>	Y	

Ref	Standard: Asterisked sections apply only to children needing level 2/3 care	Met?	Comment
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> <ul style="list-style-type: none"> a. Ventilation b. Resuscitation c. Transporting ventilated children* d. Professional boundaries e. Child safeguarding f. Working in the home environment* (where applicable) g. Infection control and disposal of clinical waste <p>Where appropriate for the needs of the child:</p> <ul style="list-style-type: none"> h. Tracheostomy care* i. Oxygen via a ventilator* j. Humidification* k. Saturation monitoring l. Urinary catheterisation* m. Spinal care* n. 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>At the time of the review the service was using an out of date version of the competence framework and some sections were incomplete. Reviewers suggested they start to use the on-line national competences, available since 2010. Also, the service did not assess staff in the home environment although they had started to do this.</p>
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> <ul style="list-style-type: none"> a. Have access to each child's latest Personal Care Plan (QS PP-103) b. Have information about the equipment used and maintenance arrangements c. 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>	Y	

Ref	Standard: Asterisked sections apply only to children needing level 2/3 care	Met?	Comment
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	Staff were not reviewed every two months.
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 	N/A	
PP-208	<p>Nominated Lead for Transition</p> <p>The service should have a nominated lead for transition to adult care for young people on long-term ventilation.</p>	Y	
PP-209	<p>Emotional Support for Staff</p> <p>All staff should have direct access to emotional and psychological support or counselling.</p>	Y	Emotional support for staff was offered although not always taken up.
PP-210	<p>Clinical Supervision</p> <p>All registered healthcare professionals should be offered regular clinical supervision appropriate to their role at least quarterly. This should include 'safeguarding supervision'.</p>	Y	
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	At the time of the review administrative staff had been recruited.

Ref	Standard: Asterisked sections apply only to children needing level 2/3 care	Met?	Comment
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> <ul style="list-style-type: none"> a. Physiotherapy (Monday to Friday) b. Occupational therapy (Monday to Friday) c. Dietetics (Monday to Friday) d. Speech and language therapy (Monday to Friday) e. Psychological support (Monday to Friday) f. Play support (Daily) g. 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>	N	<p>There was no local respiratory physiotherapy available in the community (point ‘a’) and the service used Birmingham Children’s Hospital for respiratory outreach. See main report. Point ‘c’ was also not met.</p>
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. Chaplain or multi-faith representative (24/7) b. Home Oxygen Assessment and Review Service* (7/7) c. Transport services for children with complex needs* (Monday to Friday) d. Social work (Monday to Friday) and Emergency Duty Team 	Y	
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	

Ref	Standard: Asterisked sections apply only to children needing level 2/3 care	Met?	Comment
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> <ul style="list-style-type: none"> 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). b. Consultant-led ENT service. 	N/A	

Ref	Standard: Asterisked sections apply only to children needing level 2/3 care	Met?	Comment
PP-401	<p>Equipment</p> <p>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. Cough assist machine <p>Each child needing level 1 ventilatory support:</p> <ul style="list-style-type: none"> a. One ventilator in the home b. 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	<p>Excellent costings were included in the continuing care reports for both consumables and equipment. Reviewers suggested the equipment list be made available electronically so that it would be more easily accessible.</p>

Ref	Standard: Asterisked sections apply only to children needing level 2/3 care	Met?	Comment
PP-501	<p>Guidelines on Initiation of Ventilation</p> <p>Guidelines on initiation of ventilation should be in use covering at least:</p> <ol style="list-style-type: none"> Involvement of the family and consent for initiation of long-term ventilation Multi-disciplinary discussion involving staff of the Tertiary Children's LTV Service* 	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> <ol style="list-style-type: none"> Pressure sores and tissue viability Tracheostomy care* Ventilation Suction of natural and artificial airways* Oxygen therapy* Saturation monitoring Resuscitation Gastrostomy* Venous thrombo-embolism assessment and prevention* 	N	Guidelines for points 'c', 'e' and 'f' were not available and those for points 'b' and 'd' were in draft form. All other guidelines were in place.
PP-601	<p>Operational Policy</p> <p>The service should have an operational policy covering, at least:</p> <ol style="list-style-type: none"> Criteria and arrangements for referral into the service Handover to and from 24/7 Children's Nursing Support (QS PP-205) and ensuring all appropriate information is available Criteria and arrangements for accessing the Tertiary LTV Advice Service (QS PP-207) 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"> For training To provide care for the child during a short break or hospital stay System for support for staff (QS PP-209) Discharge to the care of 'universal' children's services or specialist disability services Criteria and arrangements for referral to children's palliative care services 	Y	
PP-602	<p>Discharge Planning Guidelines</p> <p>Network-agreed guidelines for discharge from hospital (QS PY-602) should be in use.</p>	N	Guidelines were not available and the service was not aware of the network guidelines available.

Ref	Standard: Asterisked sections apply only to children needing level 2/3 care	Met?	Comment
PP-603	<p>Multi-Disciplinary Care Planning Policy</p> <p>A policy covering multi-disciplinary care planning and continuing care assessment should be in use covering at least:</p> <ul style="list-style-type: none"> a. Arrangements for multi-disciplinary care planning covering all aspects of QS PP-103, involving: <ul style="list-style-type: none"> i. The child themselves and their family ii. The child's general practitioner iii. The child's 'key worker'*, community children's nurse, Tertiary Children's LTV Service consultant and community paediatrician iv. All relevant staff from the service (QS PP-203) v. Representatives of other services involved in the care of the child vi. Social work, education and relevant voluntary service representatives vii. Documentation of Personal Care Plan and Care Package in the Personal Care Record (QS PP-103) b. Agreement and documentation of: <ul style="list-style-type: none"> i. Continuing Care Assessment* (if applicable) ii. Agreed Care Package* iii. Agreement of Care* iv. Emergency Health Care (Escalation) Plan v. Ventilation Care Plan vi. Tracheostomy Care Plan* (if applicable) vii. Risk Assessment viii. Power Failure Plan ix. Equipment Failure Plan x. 'Going Out' Plan, including care of equipment* xi. Overnight Checklists* xii. Stock Checklists* c. Confirmation of the child's: <ul 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 d. Communication of any changes to the plan of care to the: <ul 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 School Health Care Plan e. Consideration of and acting on safeguarding issues 	-	This Quality Standard was not reviewed as it may duplicate other Quality Standards.

Ref	Standard: Asterisked sections apply only to children needing level 2/3 care	Met?	Comment
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	Weekly review was not yet in place.
PP-605	<p>Guidelines on Communication with Ambulance Service</p> <p>The ambulance service should be informed of:</p> <ol style="list-style-type: none"> 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 When the child of young person is no longer at a residential address. 	Y	
PP-606	<p>Equipment Policy</p> <p>An Equipment Policy should be in use covering responsibilities and arrangements for:</p> <ol style="list-style-type: none"> Setting up equipment Maintenance and servicing of equipment Emergency replacements Replacement of breakages Emergency contact details Return of equipment when no longer needed 	N	An equipment policy was not yet in place.
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	The equipment register was not available electronically (paper form only) and was not available to anyone on call 24/7. See also Quality Standard PP-606.

Ref	Standard: Asterisked sections apply only to children needing level 2/3 care	Met?	Comment
PP-608	<p>Guidelines on Transition to Adult Care</p> <p>Guidelines on transition to adult care should be in use, covering:</p> <ul style="list-style-type: none"> a. Age guidelines for timing of transition b. Involvement of the young person and their family in the decision about transition c. Multi-disciplinary planning of the transition with primary health care, social care, education service and adult services d. Joint meetings with the young person, their family and children's and adult services prior to transition e. Responsibility for key working functions during the transition period f. A preparation period and education programme relating to transition to adult care g. Arrangements for monitoring during the time immediately after transition to adult care 	Y	
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> <ul style="list-style-type: none"> a. Special Educational Needs services b. Transport services* c. Equipment supply and maintenance services d. Acute Trusts to which children are normally admitted with acute exacerbations (if not the Tertiary Children's LTV Service) 	N	Reviewers did not see any evidence of liaison meetings with support services.
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>	N	The service had not been represented at the network meetings for approximately 18 months.

Ref	Standard: Asterisked sections apply only to children needing level 2/3 care	Met?	Comment
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	Some data were collected (points 'a', 'b', 'd' and 'g'). The service had started to address other aspects of data collection.
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 (QA PN-501 and PP-502) c. PAT Testing and Equipment Service and Maintenance 	N	Audit for point 'c' was not available. Other aspects of the Quality Standard were in place.
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>	N	At the time of the review there were no arrangements for multi-disciplinary review and learning. The service had plans for addressing this.
PP-799	<p>Document Control</p> <p>All policies, procedures and guidelines should comply with Trust or employing organisation's document control procedures.</p>	Y	

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PALLIATIVE CARE FOR CHILDREN AND YOUNG PEOPLE

Ref	Standard	Met?	Comment
PN-101	<p>General Support for Children, Young People and their Families</p> <p>Children, young people and their families 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. Social care d. Benefits advice e. Spiritual support f. <i>HealthWatch</i> or equivalent organisation 	Y	
PN-102	<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. Organisation of the service, including times available (community services) c. Service routines such as meal times, visiting times and ward routines (if applicable) d. Staff and facilities available, including facilities that families may want to use such as multi-faith rooms, accommodation, shops, canteens or restaurants e. Transport facilities, car parking and arrangements for subsidised car parking costs (if available) f. How to contact the service for help and advice, including 'out of hours' 	Y	

Ref	Standard	Met?	Comment
PN-103	<p>Condition-Specific Information</p> <p>Children, young people and families should be offered discussion and access to written information about their condition (see note 2), including:</p> <ul style="list-style-type: none"> a. Description of their condition and its impact b. Medication, including what it is for, when to take it, storage and possible side effects c. Management of acute and chronic changes in health d. Education, including planning together how to get help and support to continue education 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 and how to access charitable funding and other resources i. Transport and mobility j. Other local services available for children and young people with palliative and complex care needs and how to access them k. Advance Care Planning l. Pre- and post-bereavement support and care for children, young people and families m. Relevant voluntary organisations and support groups, including 'Together for Short Lives' n. Where to go for further information, including useful websites 	Y	<p>There was limited detail on specific medication, including documentation of when patients/carers had been given it. Some aspects of this standard were covered by the Advanced Care Planning information. Good pre- and post-bereavement support and psychological support was available from within the team. Bereavement support was also commissioned from a Bereavement Service.</p>

Ref	Standard	Met?	Comment
PN-104	<p>Personalised Care Planning</p> <p>Each child and young person and family should have the opportunity for discussion and agreement of their plan of care. This should be confirmed in a written Personal Care Record which is communicated to all services involved in their care and which is updated regularly and reviewed at least annually. The plan of care should cover:</p> <ul style="list-style-type: none"> a. Agreed goals, including 'parallel planning' goals b. Therapeutic interventions (pharmacological and non-pharmacological) c. Equipment used d. Care provided by the child, young person and their family and any training needed e. Name of the person taking a 'key working' function and their contact details f. Names and contact details of professionals and services involved in their care g. Education and education plan covering, at least, nursery, school or college attended and arrangements for liaison with them h. Choices and options for short breaks i. Housing and any housing adaptations needed j. Religious, spiritual and cultural needs k. Transport arrangements and transport needs l. Early warning signs of problems and what to do if these occur, including 'just in case' medication (if appropriate) m. How to access advice and support, including out of hours (QS PP-205) n. Planned review date and how to access a review more quickly, if necessary. o. Transition to adult services (if applicable) <p>This QS should be met once for each child or young person (not once in each service).</p>	Y	<p>This standard was met but see main report in relation to key working. There was a process in place to ensure that a child's wishes were included during their life but this was not reflected in the documentation. Reviewers suggested this could be more explicit. Further information was needed for transport options (point 'k').</p>

Ref	Standard	Met?	Comment
PN-105	<p>‘Key working’</p> <p>Each child and young person should have someone taking a ‘key working’ function 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 or young person and their family and providing information, support and advice covering all aspects of Qs PP-102 and PP-103 Liaison with the child or young person’s named Community Children’s Nurse Informing other services involved with the child or young person about changes to their condition or plan of care (QS PP-103) Informing the child or young person’s nursery, school or college of changes to their condition, plan of care (QS PP-103) or Advance Care Plan (QS PN-106) Liaison with other services, including education and housing services, to advocate for needs of the child or young person and their family Initiating a multi-disciplinary care planning meeting in order to review the child or young person’s plan of care if this is needed before the next planned review date (QS PP-603) Initiating and / or participating in multi-disciplinary discharge planning (QS PP-604) Considering whether a Common Assessment Framework (or equivalent) should be opened to prevent or support periods of instability or crisis Consideration of and acting on safeguarding issues Handover to the next person taking a ‘key working’ function with the child or young person (if required) <p>This QS should be met once for each child or young person (not once in each service).</p>	N	See main report.
PN-106	<p>Advance Care Plan</p> <p>Each child or young person and their family should have an Advance Care Plan. The Advance Care Plan should be communicated to all relevant services involved in the care of the child or young person and should include a review date. If an Advance Care Plan is not yet appropriate, this should be documented in the child or young person’s medical record.</p>	Y	The policy required finalising.

Ref	Standard	Met?	Comment
PN-107	<p>Family Involvement in Care</p> <p>Family members should have information, encouragement, support and training to enable them fully to participate in decisions about, and in the care of, their child.</p>	Y	The service was delivering person-centred care but this was not reflected in the documentation. Reviewers suggested that encouraging and enabling family involvement could be made more explicit in care plans.
PN-108	<p>Facilities for Families</p> <p>Services providing overnight care should have the following facilities for families:</p> <ol style="list-style-type: none"> A comfortable chair at the child's bedside Somewhere comfortable to sit away from the ward or child's bedroom A quiet room for relatives A toilet and washing area A kitchen or other facility for getting hot food Changing and play areas for other young children Overnight facilities including a foldaway bed or pullout chair-bed next to the child and, ideally, accommodation on site but away from the ward or child's bedroom 'Personal care packs' for relatives who unexpectedly stay overnight Facilities for children with severe physical disability, including hoists and bath/shower equipment 	N	Most aspects of this standard were met but the toilet for parents (point 'd') was within the parent's bedroom which did not lock and was not secure. This was the only toilet for parents on the ward and therefore could not be used if other parents were using the bedroom. Parents were directed to the staff toilets if the bedroom was in use. See main report.
PN-109	<p>Play Support</p> <p>Children and young people should have access to support and opportunities for play and distraction during any painful or invasive procedures and to enable their development and well-being.</p>	Y	
PN-110	<p>Bereavement Support</p> <p>Families experiencing more complex grief should have access to a service providing ongoing, more specialist bereavement support including:</p> <ol style="list-style-type: none"> Support for the child or young person Pre- and post- bereavement support for the family, including siblings 	Y	
PN-198	<p>Assessment of Carers' Needs</p> <p>Families should have information and advice on services available to provide support and, when necessary, should be referred for an assessment of their own needs.</p>	Y	Good social care support was available.

Ref	Standard	Met?	Comment
PN-199	<p>Involving Children, Young People and Families</p> <p>The service should have:</p> <ol style="list-style-type: none"> Mechanisms for receiving feedback from children, young people and their families about the treatment and care they received. Mechanisms for involving children, young people and families in decisions about the organisation of the service. Examples of changes made as a result of feedback and involvement of children, young people and their families. 	Y	
PN-201	<p>Named Service Lead Paediatrician and Nurse</p> <p>The service should have a nominated lead paediatrician and lead nurse responsible for ensuring the service meets all applicable Quality Standards and for liaison with leads for the 'local area' (QS PZ-201) and leads of other paediatric palliative care services within the 'local area'. The lead paediatrician and lead nurse should have clinical involvement in paediatric palliative care.</p>	N	A consultant, who was not known to the service, had one session in their job plan for strategic planning but not for any clinical work within the service. A lead nurse was in place. See main report.
PN-202	<p>Staffing Levels</p> <p>The service should have sufficient staff with appropriate competences for the usual number of children and young people cared for by the service, their dependency, the complexity of their needs and, for children thought to be in the final days of life, for undertaking visits and, if necessary, providing care in the preferred place of death. Staffing should include:</p> <ol style="list-style-type: none"> Medical staff (see note 1) Nursing staff, health care assistants and support workers (see note 4) Other staff providing support and care for children and young people needing palliative care (QS PP-302) who are part of the service's 'core team'. <p>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>Community services should have sufficient staffing to care for at least two children in the final days of life or should have a contingency plan covering this eventuality and which can also be used if staffing levels are reduced due to maternity leave or long-term sickness.</p>	N	See Quality Standard PN-201 in relation to medical staff. Staffing was 'lean' and commissioners had requested a workforce plan from the service. See also main report.

Ref	Standard	Met?	Comment
PN-203	<p>Competence Framework and Training Plan</p> <p>All staff should be working towards and, when achieved, should be maintaining competences appropriate to their role in:</p> <ol style="list-style-type: none"> a. Philosophy of palliative care b. Symptom control , including: <ol style="list-style-type: none"> i. Pain evaluation ii. Pain management iii. Nausea, vomiting and reflux iv. Constipation, anorexia, cachexia and hiccough v. Mouth care, feeding and hydration vi. Dyspnoea vii. Seizures and other neurological and neuromuscular problems viii. Psychological symptoms ix. Skin symptoms c. Emergencies d. Ethics and Law e. Care immediately around the time of death f. Practicalities around death g. Advanced communication skills h. Use of palliative care equipment i. Psychosocial support j. Play support k. Working with children with emotional and behavioural difficulties l. Bereavement support <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	Some training was available but take-up appeared to be poor. There was no evidence of joint training with ward staff.
PN-204	<p>24/7 Community Support</p> <p>24/7 support and advice from a registered health care professional with competences in paediatric palliative care should be available through a single telephone number. Staff providing this service should:</p> <ol style="list-style-type: none"> a. Be aware of the children and young people who may contact them b. For children thought to be in the last days of life, be able to mobilise staff to undertake home visits or to provide care c. Have access to more specialist advice on complex symptom management (QS PP-303) d. Have access to specialist advice on the child or young person's condition. 	Y	24/7 community support was available. Support was available via a specific telephone number overnight.

Ref	Standard	Met?	Comment
PN-205	<p>Nominated Lead for Transition</p> <p>The service should have a nominated lead for transition to adult care of young people with complex and palliative care needs.</p>	Y	
PN-206	<p>Emotional Support for Staff</p> <p>All staff should have direct access to emotional and psychological support or counselling.</p>	Y	
PN-207	<p>Clinical Supervision</p> <p>All registered healthcare professionals should be offered regular clinical supervision appropriate to their role.</p>	Y	
PN-299	<p>Administrative and Clerical Support</p> <p>Administrative, clerical and data collection support should be appropriate for the number of children and young people cared for by the service.</p>	Y	At the time of the review administrative staff had been recruited.
PN-301	<p>Support Services</p> <p>The following services should be available to support children and young people with palliative care needs in the location where care is delivered:</p> <ol style="list-style-type: none"> Chaplain or multi-faith representative (24/7) Pharmacy advice (daily by telephone) Physiotherapy (daily) Occupational therapy (Monday to Friday) Dietetics (Monday to Friday) Speech and language therapy (Monday to Friday) Psychological support (Monday to Friday) Play support (for painful and invasive procedures and daily for in-patient and hospice services) Home Oxygen Assessment and Review Service (daily) Youth workers (Monday to Friday) Transport services for children with complex needs (Monday to Friday) Wheelchair assessment, supply and maintenance service (Monday to Friday) Assessments for housing adaptations (Monday to Friday) Social work (Monday to Friday) and Emergency Duty Team Bereavement support service (QS PN-110) <p>These services should be able to respond urgently to acute deterioration as well as to planned changes in care.</p>	N	Services relating to points 'c', 'e', 'j' and 'l' were not available.

Ref	Standard	Met?	Comment
PN-302	<p>Specialist Advice on Complex Symptom Management</p> <p>Staff should have 24/7 access to specialist medical and nursing advice on complex symptom management in children and young people.</p>	N	Arrangements were not clear about specialist advice from medical staff. Advice was available from the acute consultant paediatrician on call but this could involve ringing several people (see main report). Specialist advice from nursing staff was available.
PN-401	<p>Equipment</p> <p>Timely access to equipment (Appendix 6) should be available.</p>	Y	Equipment was easily accessible, including overnight.
PN-501	<p>Clinical Guidelines – Symptom Control</p> <p>Clinical guidelines should be in use covering common symptoms and problems in palliative care, including:</p> <ol style="list-style-type: none"> Pain assessment and management, including use of syringe pumps Management of nausea and vomiting Management of seizures Management of dyspnoea Management of agitation Management of secretions 	Y	The service used the WMPPCN (West Midlands Paediatric Palliative Care Network) Toolkit.
PN-502	<p>Clinical Guidelines – Tracheostomies and Long-Term Ventilation</p> <p>If the service is caring for a child or young person with a tracheostomy or on long-term ventilation then clinical guidelines on the management of tracheostomies and long-term ventilation should be in use.</p>	Y	
PN-503	<p>Pathway Guidelines</p> <p>Guidelines should be in use covering at least:</p> <ol style="list-style-type: none"> High dependency care Advance Care Planning, including wishes for life and end of life Religious, spiritual and cultural care Neonatal care Compassionate extubation Bereavement, including indications for referral to more specialist bereavement services 	N	Points 'a', 'd', 'e' and 'f' were not met. Advanced care planning was in place. For point 'd' reviewers suggested that the national BLISS guidelines could be easily adopted.

Ref	Standard	Met?	Comment
PN-601	<p>Operational Policy</p> <p>The service should have an operational policy covering, at least:</p> <ul style="list-style-type: none"> a. Criteria and arrangements for referral into the service b. Communication between: <ul style="list-style-type: none"> i. All services involved in the care of the child or young person, including two-way communication with 24/7 community support service (QS PP-205) ii. All consultants involved (when more than one) iii. The child or young person’s nursery, school or college iv. Social care v. Any other statutory and voluntary agencies involved in their care c. Arrangements for supply of equipment d. Arrangements for access to medicines outside normal working hours, including controlled drugs e. Access to short breaks, including respite in the child or young person’s home f. Involvement of family carers in providing care g. Arrangements for professional carers to work in the hospital or hospice <ul style="list-style-type: none"> i. For training ii. To provide care for the child or young person during a hospital or hospice stay h. Arrangements for support visits as well as clinical visits, including arrangements for visiting at home after the child or young person is first identified as on the palliative pathway i. Arrangements for assessment by social care for direct payments j. Arrangements, when necessary, for referral to social care for a carers’ needs assessment. k. For children thought to be in the final days of life, arrangements for undertaking visits and, if necessary, providing care in the preferred place of death l. System for support for staff (QS PP-209), including triggers for pre- and post- bereavement de-briefs m. Arrangements for accessing specialist advice on complex symptom management (QS PP-303) n. Discharge to the care of general children’s services or specialist disability services 	Y	A good policy was in place.

Ref	Standard	Met?	Comment
PN-602	<p>Communication of New Diagnosis or Changed Prognosis</p> <p>Guidelines should be in use on communication of a new diagnosis or change in prognosis covering:</p> <ul style="list-style-type: none"> a. Importance of face to face discussions in privacy b. Use of interpreter services (QS PN-101) c. Involvement of the child or young person and their family d. Provision of information for the child or young person and their family (QS PP-102) 	Y	<p>Good, child-friendly documentation for diagnosis and changed prognosis was in place. Collaborative working arrangements between the service and the acute Trust were not clear.</p>
PN-603	<p>Multi-disciplinary Care Planning and 'Key Working' Agreement</p> <p>The service should have agreed, written arrangements covering all aspects of QS PP-103:</p> <ul style="list-style-type: none"> a. Arrangements for multi-disciplinary care planning involving: <ul style="list-style-type: none"> i. The child or young person themselves and their family ii. The child or young person's general practitioner iii. All relevant staff from the service (QS PP-202) iv. Representatives of other services involved in the care of the child or young person v. Social work, education and voluntary service representatives b. Documentation of agreed plan of care in the Personal Care Record (QS PP-103) c. Allocation of person taking a 'key working' function (QS PP-105) d. Allocation of a named Community Children's Nurse e. Communication of any changes to the plan of care to all services involved f. Consideration of whether a Common Assessment Framework (or equivalent) should be opened to prevent or support periods of instability or crisis g. Consideration of and acting on safeguarding issues 	Y	<p>Multi-disciplinary care planning was good and included joint work with social care, education and Acorns Hospice. There was good collaboration on safeguarding issues. The common assessment framework (point 'f') was no longer used in Worcestershire and had been replaced with the 'Early Health' plan See main report in relation to point 'c', key working.</p>

Ref	Standard	Met?	Comment
PN-604	<p>Planning to Go Home</p> <p>Discharge planning guidelines should be in use covering:</p> <ul style="list-style-type: none"> a. Arrangements for early multi-disciplinary discussion and planning of discharge covering all aspects of QS PP-103 and involving, at least: <ul style="list-style-type: none"> i. The child or young person and their family ii. The child or young person's general practitioner iii. The person taking the 'key working' function (QS PP-105) iv. Local community service staff, local acute hospital staff and 24/7 community support service (QS PP-205) v. Education service vi. Other statutory and voluntary agencies involved in the care of the child or young person b. Arrangements for community staff to visit the child or young person in the acute hospital or hospice prior to discharge. c. Arrangements for supply of equipment (QS PP-401) d. Arrangements for <ul style="list-style-type: none"> i. Seven day supply of medicines and enteral feeding ii. Supply of 'just in case' medication (QS PN-605) e. Arrangements for handover to the service taking over responsibility for the care of the child or young person f. Arrangements for support, advice and review during the 24 hours after discharge g. Arrangements for the discharge summary to be given to the child or young person or their family and to be sent at the time of discharge by fax or email to their GP, to the lead paediatrician and lead nurse of all services involved in their care. 	Y	

Ref	Standard	Met?	Comment
PN-605	<p>'Just in Case' Medication</p> <p>A policy on 'just in case' medication should be in use which ensures:</p> <ul style="list-style-type: none"> a. Anticipatory drugs are 'written up' b. Where applicable, a Drug Administration Document is completed in advance of the discharge by a prescriber from the discharging team who is familiar with the child c. Anticipatory drugs are supplied to the family d. Appropriate advice on storage and administration is given verbally and in writing e. Communication about 'just in case' medication with the child or young person's general practitioner and all services involved in their care 	Y	
PN-606	<p>Communication with Ambulance Service</p> <p>Guidelines on communication with the ambulance service should be in use covering:</p> <ul style="list-style-type: none"> a. Informing the ambulance service of a child or young person needing palliative care at home and any special arrangements, including Advance Care Plans (if applicable) b. Informing the ambulance service when the child of young person is no longer at a residential address. 	Y	

Ref	Standard	Met?	Comment
PN-607	<p>Care around the time of death</p> <p>Guidelines on care around the time of death should be in use covering, at least, arrangements for:</p> <ol style="list-style-type: none"> a. Rapid discharge, including: <ol style="list-style-type: none"> i. Agreement with receiving services that care can be provided by them ii. Communication with the general practitioner iii. Communication with all services involved in the child or young person's care b. If necessary, review of the choice of preferred place of death and transfer to an alternative setting c. Clinical review and assessment, including liaison with the general practitioner and 'local area' lead palliative care paediatrician d. Support for the family, including in the period immediately after the death e. Supply and disposal of medication and oxygen f. Supply and removal of equipment g. Verifying, certifying and registering the death h. Care and, if applicable, transfer of the child's body i. Ensuring compliance with the Child Death Review Process <p>Guidelines should ensure appropriate recognition of families' spiritual and cultural needs.</p>	Y	
PN-608	<p>Transition to Adult Care</p> <p>Guidelines on transition to adult care should be in use, covering:</p> <ol style="list-style-type: none"> a. Age guidelines for timing of transition b. Involvement of the young person and their family in the decision about transition c. Multi-disciplinary planning of the transition with primary health care, social care, education service and adult services d. Joint meetings with the young person, their family and children's and adult services prior to transition e. Responsibility for key working functions during the transition period f. A preparation period and education programme relating to transition to adult care g. Arrangements for monitoring during the time immediately after transition to adult care 	Y	

Ref	Standard	Met?	Comment
PN-609	<p>Local Clinical Coordination</p> <p>Representatives of the service should meet with the 'local area' lead palliative care paediatrician and lead nurse (QS PZ-201) on a regular basis to review the clinical care of children and young people needing palliative care. This may be achieved through a Clinical Forum involving all services providing palliative care for children and young people in the 'local area'.</p>	Y	There were several multi-agency meetings although there was no clinical forum.
PN-610	<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"> a. Special Educational Needs services b. Transport services c. Equipment supply services d. Service providing social care for children with disabilities 	Y	See good practice section of main report.
PN-611	<p>Liaison with Other Services</p> <p>If the 'local area' lead paediatrician or lead nurse is employed by the service:</p> <p>The 'local area' lead paediatrician and lead nurse should:</p> <ol style="list-style-type: none"> a. Take a lead role in the 'local area' Paediatric Palliative Care Planning Group (QS PZ-604) b. Meet regularly with each service providing paediatric palliative care in the local area to discuss clinical coordination and improving clinical care (QS PN-609) c. Attend meetings of the Regional Palliative Care Network and communicate relevant issues to local services d. Meet at least annually to review arrangements for liaison and address any problems identified with: <ol style="list-style-type: none"> i. Service providing specialist advice on complex symptom management (QS PP-303) ii. Newborn network iii. Relevant condition-specific paediatric services 	Y	

Ref	Standard	Met?	Comment
PN-701	<p>Data Collection</p> <p>There should be regular collection of data and monitoring of:</p> <ol style="list-style-type: none"> a. Number of children cared for by the service b. National minimum data set (when agreed) c. Other key performance indicators agreed by the 'local area' paediatric palliative care planning group 	Y	
PN-702	<p>Audit</p> <p>The services should have a rolling programme of audit of:</p> <ol style="list-style-type: none"> a. Completeness of the Personal Care Record (QS PP-103), including whether reviewed at least annually b. Self-assessment against the: <ol style="list-style-type: none"> i. ACT Integrated Palliative Care Pathways Standards ii. ACT Neonatal Care Pathway iii. ACT Transition Care Pathway iv. ACT Extubation Pathway c. Compliance with clinical guidelines (QS PP-501) d. Supply of equipment within expected timescales (QS PP-401) e. Calls to the 24/7 community support service (QS PP-205) outside normal working hours f. Use of Advance Care Plans 	Y	
PN-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	
PN-799	<p>Document Control</p> <p>All policies, procedures and guidelines should comply with Trust (or employing organisation's) document control procedures.</p>	Y	Some documents were going through Trust approval procedures. The service should ensure all documents are finalised.

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COMMISSIONING - LONG-TERM VENTILATION SERVICE

Ref	Standard	Met?	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 Error! Reference source not found.).</p>	N	Commissioners were not aware of network-agreed discharge guidelines.
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 School 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	

Ref	Standard	Met?	Comments
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	The service specification made available by the Long-Term Ventilation Network, which included quality indicators, was not being used. See main report.

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COMMISSIONING - PALLIATIVE CARE FOR CHILDREN AND YOUNG PEOPLE

Ref	Standard	Met?	Comment
PZ-201	<p>‘Local Area’ Lead Palliative Care Paediatrician and Lead Nurse</p> <p>Commissioners should agree the lead palliative care paediatrician and lead nurse for the ‘local area’ for paediatric palliative care services. The lead palliative care paediatrician should have achieved level 3 competences in Paediatric Palliative Medicine. Both the lead paediatrician and lead nurse should have regular clinical involvement in paediatric palliative care, normally within a local service. These roles should be recognised in the commissioning of the service through which the lead paediatrician and lead nurse is employed (QS PZ-603).</p>	N	See Quality Standard PN-201 in relation to the Lead Consultant. A lead nurse was in place.
PZ-501	<p>Safeguarding Policy</p> <p>The local Safeguarding Policy should include specific consideration of the needs of children and young people with disabilities and life-limiting conditions.</p>	Y	

Ref	Standard	Met?	Comment
PZ-601	<p>Commissioning: Paediatric Palliative Care</p> <p>Services to meet the local children and young people needing palliative care should be commissioned for an agreed 'local area', including:</p> <ul style="list-style-type: none"> a. Community-based services b. Acute hospital services c. Hospice care d. 24/7 Community telephone support (QS PP-205) <p>The model of services commissioned should take into account sustainability of service quality and, in particular:</p> <ul style="list-style-type: none"> i. arrangements for providing care in the preferred place of death for children thought to be in the final days of life ii. ability of services to respond if two children need end of life care at the same time. <p>Criteria and arrangements for referral to and discharge from each service should be specified.</p>	N	Reviewers were not shown a service specification for paediatric palliative care.
PZ-602	<p>'Local area' Paediatric Palliative Care Planning Group</p> <p>A multi-agency group involving, at least, representatives of children, young people and their families, commissioners, all community-based, acute and hospice paediatric palliative care services for the 'local area' (QS PZ-603), education, social care, and other statutory and voluntary organisations involved in the care of children and young people with palliative care needs should meet at least annually to:</p> <ul style="list-style-type: none"> a. Review the number of children cared for by each service b. Agree and review key performance indicators for each service c. Review issues of relevance identified through local clinical coordination meetings (QS PN-609) d. Agree and review the results of any 'local area'-wide audits (QS PP-702) e. Review issues raised at regional network meetings and identify implications for local services f. Agree and review the strategy for paediatric palliative care for the 'local area' 	N	No specific local area group was in place although several joint commissioning meetings took place.

Ref	Standard	Met?	Comment
PZ-701	<p>Quality Monitoring: Paediatric Palliative Care Services</p> <p>Commissioners should regularly review the quality of services provided by paediatric palliative care services (QS PP-701). Appropriate action should be taken to tackle any issues identified through quality monitoring.</p>	N	No service specification containing agreed quality indicators was seen by reviewers.

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