

SCHEDULE 2 – THE SERVICES

A. Service Specifications

Service Specification No.	E07/S/c
Service	Paediatric Long Term Ventilation
Commissioner Lead	
Provider Lead	
Period	12 Months
Date of Review	

1. Population Needs

1.1 National/local context and evidence base

National Context:

Recent clinical advances in Neonatal and Paediatric Intensive Care have increased the incidence of survival of children with life threatening or life limiting conditions. Over the same period technological advances have produced a range of portable, easy to maintain, reliable and efficient mechanical ventilators. As a result, children who have long-term breathing difficulties needing either temporary or permanent ventilatory assistance have an increased potential for survival and must be offered an integrated care pathway from hospital to home and coordination of Long Term Ventilation (LTV) specialist input across organisational boundaries.

Children on long term ventilation are a high cost group with complex and varying underlying medical conditions requiring input from multiple teams, including among others, neonatal intensive care, paediatric intensive care, paediatric respiratory medicine, cardiology, ENT, spinal injury, neuromuscular and neurodisability specialists, as well as access to palliative care.

Ventilation can be delivered via a tracheostomy (invasive ventilation) or through a mask or other device that is not directly connected to the airway (non-invasive ventilation). Most tracheostomy ventilated children start their journey in a critical care environment and have already had intensive medical input. Children on complex non-invasive ventilation often have underlying co-morbidities or associated life limiting illness, and these children require

coordination of care across the relevant specialisms within paediatric medicine, as well as a clear pathway of transition to adult services.

Most children on long term ventilation progress to a point of medical stability where their clinical needs can be met outside of the hospital environment. However, children on invasive long term ventilation (LTV) or complex non-invasive ventilation can remain in an inappropriate intensive care or hospital environment while awaiting a home care package to be established in the community. Work is taking place nationally to improve discharge processes in order to reduce inappropriate lengths of stay.

The scope of this specification covers children who have long term ventilation initiated on a Paediatric or Neonatal Intensive Care Unit, regardless of whether the interface for delivery of that ventilation is mask or tracheostomy.

Evidence base

Currently, the numbers of LTV children are recorded separately by each LTV centre and collation of this data nationally is not routinely available. Recent medical literature from the UK demonstrates a significant rise in number of children on long term ventilation (Wallis et al 2010, Goodwin et al 2011), although the population remains a relatively small volume, specialised and high cost one. From recent review undertaken for the Paediatric Critical Care Clinical Reference Group (CRG the average length of hospital stay from identification of the need for long term ventilation to discharge home is an average of 7-9 months, which has only improved marginally in the past 20 years.

As part of a PIC CRG stakeholder engagement exercise it was possible to determine that there are approximately 80-100 new onset tracheostomy ventilated children presenting in PICU per year (anticipated maximum 125 per year). No data are available on the underlying diagnostic groups but professionals report that there is a trend towards increasing medical complexity. A proportion of these children will wean off ventilation, some will succumb to their underlying life limiting condition, and others will eventually progress to adult services but there is no database available to demonstrate outcomes of institution of ventilation.

There are an increasing number of complex children managed on non-invasive ventilation, even in the newborn period and early infancy. For example current practice for Congenital Central Hypoventilation Syndrome includes the option of tracheostomy or mask ventilation depending upon local clinician preference and the needs of the child and family. Regardless of interface the needs and level of the patient remain significant and may require a complex package of care to be delivered in the home.

From the review undertaken on behalf of the Paediatric Critical Care CRG the number of tracheostomy ventilated children managed out of hospital is approximately 250-275, with a further 1000-1300 children with complex needs dependent upon non-invasive ventilation under specialist respiratory follow-up.

The model of care for all long term ventilation children is for them to be cared for in a normal home environment. The Royal College of Paediatrics and Child Health's Modelling the Future paper recommends that services for children with long-term conditions could be greatly improved if they were commissioned according to individual pathways of care. The child who remains in an intensive care setting may be a long distance away from parents and carers who may have limited resources to travel and carry out other family responsibilities.

Furthermore the Children’s and Young People’s Health Outcomes Forum (2013) has called for better integration of care and services around the child and family.

The Department of Health Continuing Care Framework for Children and Young People provides a tool for assessing whether a child has ongoing complex needs and requires a home care package and provides exemplar timeframes for some of the key tasks required to achieve timely hospital discharge and care at home.

Children on Long Term Ventilation who remain, inappropriately, in critical care beds may restrict the ability to provide paediatric critical care services for elective episodes of care. This may lead to cancellations of operations and outcome measures not being met in other clinical services.

For the critically ill child, limited access to the closest Paediatric Critical Care Unit may cause delayed transfer, and the need for the child to be transported further to receive critical care. Restriction in accessing paediatric critical care services may not only have an adverse impact on meeting the needs of the local population but can also lead to capacity problems in other specialist services.

Currently the financial cost of the hospital episode for recent onset complex long term ventilation is high due to expensive resources being utilised inappropriately and for longer lengths of stay and additional costs incurred through out of area admissions.

2. Outcomes

2.1 NHS Outcomes Framework Domains & Indicators

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

Key Outcomes*:

1. Providers of LTV services keep robust data for every patient with at least the following information available to commissioners and service managers:

- Number of patients entering LTV integrated discharge pathway
- Number of patients exiting LTV integrated discharge pathway
- Availability of identified Hospital Key Worker (or team of HKWs)
- Weekly report of 'Medical Stability'
- Monthly report of 'Multidisciplinary Discharge Planning Meetings'
- Identify and report episodes of medical instability during discharge of medically stable LTV patient
- Date of Fit for Discharge from ICU/HDU to ward (FFD-ICU)
- Date of Fit for Discharge from hospital to community services (FFD-HOSP)
- Identification of health, social, housing delays to hospital discharge
- Aggregated length of stay post fit for discharge (FFD-HOSP)
- Exception report for LTV children with Hospital Length of Stay > 90 days from FFD-HOSP

(Domain: 2,4)

2. Appropriate training provided (to enable the child to be cared for safely in the home environment) to parents and carers of LTV children, including at least annual updates or as required according to the needs of individual cases (Domain: 1,2,3,4,5)
3. Personal care plan available (including an Emergency Health Care Plan) at the point of discharge, agreed by the MDT and shared with community professionals and parents (Domain: 2,3,4)
4. Follow up plan for every patient, agreed at final MDT meeting/discharge, including clear plan for shared care between LTV centre and local clinical teams (Domain: 2,3,4,5,)

3. Scope

3.1 Aims and objectives of service

3.2 Service description/care pathway

The service model provides multidisciplinary care throughout a hospital to home integrated care pathway for children on long term mechanical ventilation, regardless of ventilator interface as long as the patient journey starts in a Paediatric or Neonatal Intensive Care Unit. Transitional care or 'step down' facilities in or out of hospital, should be considered part of the hospital to home pathway and should follow the standards agreed by the local or regional clinical network and should have a process in place for facilitating timely and safe transition to home. Providers and commissioners should note that once a patient has been medically stable on LTV for 90 days, commissioning responsibility and charges pass to local Clinical Commissioning Group commissioners.

The scope of this specification does not include the individual home care packages, which will be commissioned by the Clinical Commissioning Groups (CCGs) or groups of CCGs in liaison with their local services, education and housing departments.

Any child in Paediatric or Neonatal Critical Care who is being considered for long term home

ventilation will be referred to the local LTV specialist before a final decision to progress down the LTV pathway.

Before elective tracheostomy for invasive mechanical ventilation there must be a process of consent for long term ventilation in the home (in addition to the standard surgical consent for tracheostomy). As part of this process the child and family will have the opportunity to discuss long term ventilation with a specialist LTV team and will have access to 'condition specific' information

A second opinion will be sought where there is concern that long term ventilation is not in the child's best interests on the grounds of futility.

As part of the consent process for long term ventilation there will be an agreement to information sharing across agencies (health, social services, education, commissioning) and parents or carers will receive specific guidance on the planned discharge pathway from hospital to home.

All children considered for tracheostomy will have a formal assessment of their potential to wean by a specialist LTV or Respiratory/PICU team. A structured approach to weaning must be in place for all children on long term ventilation, whether in hospital or the community, with the aim of delivering the least invasive and least intrusive form of respiratory support that will support the best quality of life as well as safety of the child. Specialist centres will provide advice or outreach to other providers within their region to support a structured approach to weaning.

Where invasive long term ventilation is being undertaken for a child with a life limiting condition there will be agreed written guidance around the end of life pathway and advanced care plan, including guidelines for treatment of intercurrent illness, escalation of therapy, resuscitation and emergency protocols, that is agreed between the family and professional multidisciplinary team. The agreement must be shared with all key professionals involved with the child in hospital and community services. The guideline must be updated on a regular basis with the frequency dictated by the needs of the child but will be reviewed at least annually in children under the long term care of community services.

Every ventilator dependent child who is an inpatient in hospital and who needs a Complex Home Care Package (CHCP) will have an identified Hospital Key Worker (HKW) or team of HKW's. The HKW should review the child and produce a weekly status report that includes (a) medical stability and (b) capture of dates when the child is medically fit for discharge from an intensive care or high dependency bed, and when they are medically fit for discharge from hospital to the community (see below). This would allow more accurate data on acute and community sector resources and enable continuous improvement of service delivery. The HKW should communicate directly with the Community Key Worker (CKW) and should enable sharing of information through Multidisciplinary Team Meetings (MDT) which should be held on a four weekly basis while the child is in hospital.

The LTV hospital to home discharge pathway will commence at the point of identification of the potential for chronic home ventilation. Children awaiting hospital discharge should be tracked along the pathway, including weekly assessment of medical stability and readiness for discharge to enable timely transition out of intensive care or high dependency to a more appropriate environment while the home care package is being established. The integrated

care pathway will follow the child and family and cross organisational boundaries to ensure consistent care and communication throughout the patient journey.

Specialist follow up of the ventilator dependent child should allow for review as a minimum at 3, 6, and 12 months after hospital discharge. Following this a process for team review around the child and assessment of personal care plans and parent/carer competency in basic life support should be in place on an annual basis, or more often depending upon the needs of the child and family.

LTV services will network together to support local services by, wherever possible, standardising competency frameworks and education and training materials across a local area or region.

The LTV specialist services, NHS England Commissioners and CCG commissioners of home care will work with local authorities, education and housing departments to create a joined up approach to timely hospital discharge and shared standards of care for children on chronic home ventilation. This should incorporate a structured approach to social and housing issues and exploration of standardisation and procurement of equipment by the community care provider with the support of the LTV specialist teams.

A child on the LTV integrated care pathway must have an identified lead Consultant who will provide consistent communication around the needs of the child and family and ensure that the medical aspects of the child's care are being met, and that these have been considered and communicated as part of the risk assessment for transfer of care closer to home. Communication between hospital and community providers is essential in order to maintain objectives and a structured process of sharing information in the interests of the child is essential.

The multidisciplinary team (MDT) must include, but is not restricted to acute and primary sector health care workers (medical, nursing and allied health including physiotherapists, speech and language therapists, occupational therapists, dieticians, psychologists), social workers, housing officers, and representatives from the education sector. All children on the LTV pathway should have access to age appropriate play therapy or education.

The MDT process should:

- will provide a central source of information for hospital and community professionals and ensure that all non-medical needs of the child and family are met.
- Provide a 'provisional discharge date' which should be agreed at the first MDT meeting.
- a 'Fit for Discharge from Hospital' date (when the child's *medical* needs can be met out of hospital) will be agreed as part of the MDT process
- Ensures collation of clinical updates with a problem based approach resulting in a clear set of actions with allocated responsibility.
- Improve the efficiency of hospital discharge. Any actions agreed at an MDT meeting must be started, and whenever possible, completed *before* the next MDT meeting under the supervision of the HKW.
- Provide a report from the MDT meeting which should be shared with key professionals from hospital and community, as well as with the family and GP.

The MDT process must ensure that all children on the pathway have a Personal Care Plan (PCP) that includes, but is not restricted to, (a) escalation management in an emergency (b)

list of essential equipment to take when out of the home environment (c) guidelines on communication with the ambulance service and local accident and emergency services (d) notification of utility companies (e) an equipment policy that includes service arrangements and guidance in the event of breakdown, (f) a clear plan for follow-up.

Education and training support and competency assessments will be delivered by those experienced in LTV and tracheostomy care, and be freely available to parents (or primary carers) and other members of the immediate family. For a ventilator dependent child identified in neonatal or paediatric intensive care this training is essential in order to facilitate safe transition to home, and should be commenced as soon as possible after the child has been identified as requiring LTV.

Specific reporting of outcomes along the LTV hospital to home discharge pathway will be defined by commissioners of this pathway and a process of escalation must be in place in order to address any avoidable delays in discharge that are identified during the inpatient stay.

3.3 Population covered

The population includes all children initiated on long term mechanical ventilation, regardless of ventilator interface as long as the patient journey starts in a Paediatric or Neonatal Intensive Care Unit. Any child in Paediatric or Neonatal Intensive Care or Paediatric High Dependency who is being considered for long term ventilation and who requires a period of informed consent, or trial of weaning, is included in order to provide access to specialist LTV and respiratory teams.

Regardless of ventilator interface there must be recognition of the level of dependence on ventilation in determining clinical standards along the patient journey, whether the child is in hospital, in a transitional or step down unit, in long term residential care or respite, or at home. The LTV professional network will develop clinical standards that can be agreed at a regional or national level.

The National Framework for Children and Young People's Continuing Care (2010*currently being updated) has the following definition:

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

Additional information on level of dependency should be considered to help inform the care package and level of supervision required as per the example below.

If disconnected from the ventilator the patient:

- will be immediately compromised

- is likely to be compromised within ten minutes
- is likely to be compromised within one hour
- is likely to be compromised over several hours
- is unlikely to be compromised

A pathway of transition to adult services will be in place for those patients who remain ventilator dependent during adolescence, and long term ventilation services for adults will take over the long term and acute care for young adults who have reached the age of 19 and above. Planning for transition should take place well in advance of the physical transfer date to optimise the quality of the transition process.

3.4 Any acceptance and exclusion criteria and thresholds

Referral Source

- Neonatal Intensive Care Units
- Paediatric Critical Care Units
- Paediatric High Dependency Units
- Paediatric specialist consultants (e.g. respiratory, cardiology, neurology, neuromuscular)

Acceptance Criteria

- Children on paediatric or neonatal intensive care under consideration for long term ventilation
- Children on paediatric or neonatal intensive care under specialist weaning review
- Children on any form of respiratory support via tracheostomy
- Children with complex needs on non-invasive ventilation initiated in a neonatal or paediatric intensive care unit, or high dependency unit.
- Children on any level of respiratory support (including CPAP) with a critical upper airway or lower airway abnormality regardless of ventilator interface
- Children on invasive or non-invasive mechanical ventilation who are not medically fit for discharge from a paediatric or neonatal critical care unit.
- Patients may require care in a PCCU if they are in the process of transitioning to alternative permanent long-term ventilation (LTV) facilities (possibly requiring home adaptations), or to palliative care placements. However, once a patient has been medically stable on LTV for 90 days, commissioning responsibility and charges pass to local Clinical Commissioning Group commissioners.

Exclusion Criteria

- Overnight respiratory support for uncomplicated sleep disordered breathing
- Children receiving short term respiratory support during an inpatient spell on a paediatric ward, or paediatric intensive care or high dependency unit where the aim is to wean off respiratory support before hospital discharge.
- Children initiated on long term ventilation in a setting outside of intensive care or high dependency units. (these children currently sit under paediatric medicine respiratory subgroup)

Medical Stability

Defining “Medical Stability” for a child on long term ventilation is challenging but is important in informing the transition from hospital to home. A clear and consistent approach to capturing this information will assist in evaluating and planning the resource required for this population, as well as providing consistent reporting of avoidable delays in hospital discharge for an individual patient. Two clear decision points should be captured which are (1) when a patient is medically fit to ‘step-down’ from the paediatric intensive care or high dependency unit to a paediatric ward or local centre (FFD-ICU) and (2) when a patient is medically suitable to step down from hospital to home (FFD-HOSP). There will be some discretion required on a case by case basis but applying these criteria consistently would allow more robust analysis of service integration and avoidable delays in achieving care closer to home.

- **Fit for Discharge from Paediatric Intensive Care or High Dependency Care to Paediatric Ward or LTV unit (FFD-ICU) based on “Medical Stability” information below:**
 - stable airway present
 - stable oxygen requirements (if required) usually less than 40%
 - arterial carbon dioxide tensions can be maintained within safe limits on ventilatory equipment that can be used on the ward (in some centres this would include children on noninvasive respiratory support using high flow or CPAP from compressed gases)
 - nutritional intake is adequate to maintain expected growth and development (the child may not yet be established on full enteral feeds)
 - other *acute* medical conditions are under control with no life threatening episodes of aspiration and stable acid-base and metabolic status

**An agreed medically fit for discharge (FFD-ICU) date would be captured when all of the above criteria have been satisfied for a period of two continuous weeks (or sooner at the discretion of the lead ICU and LTV consultant depending upon the ICU course and condition of the individual patient)*

- **Fit for Discharge from Hospital to Community Based Services (FFD-HOSP) based on “Medical Stability” information below:**
 - stable airway present
 - stable oxygen requirements (if required) usually less than 40%
 - arterial carbon dioxide tensions can be maintained within safe limits on ventilatory equipment that can be operated by the family or carer(s) at home
 - nutritional intake is adequate to maintain expected growth and development and is delivered by a route that can be managed by the local care provider
 - all other medical conditions are well controlled, including stable doses of medication

**An agreed medically fit for discharge from hospital (FFD-HOSP) date would be captured when all of the above criteria have been satisfied for a period of two continuous weeks (or sooner at the discretion of the LTV consultant in conjunction with the local care provider)*

3.5 Interdependencies with other services/providers

Children who require initiation of long-term invasive mechanical ventilation are usually identified during an inpatient spell in a neonatal or paediatric intensive care unit. Neonatal or Paediatric Critical Care practitioners will therefore be necessary in the early course of the

patient journey and would deliver a service consistent with those specialty standards. Access to specialist paediatric ear, nose and throat (ENT) surgeons for inpatient and follow up care is essential for children undergoing tracheostomy.

Access to specialist paediatric respiratory specialist services is necessary in order to offer specialist respiratory investigations, to assess adequacy of ventilatory support, for example through clinical assessment and sleep studies. Active evaluation of the potential to wean from ventilatory support should be undertaken on a regular basis before and after hospital discharge. Specialist respiratory support, including physiotherapy, can be delivered from a Paediatric Respiratory Specialist Service or through a Long Term Ventilation Service, or a combination of both.

Links to other specialist services will depend upon the need of the individual child and family and may include need for access to specialist support from psychology, psychiatry, neuromuscular, neurology, neurorehabilitation, spinal injuries, orthopaedics, metabolic and endocrine, cardiology and cardiac surgery, and palliative care.

A multidisciplinary team approach must include input from paediatric psychology, physiotherapy, occupational therapy, dietetics, speech and language therapy, play specialists, and social services. Access to the multidisciplinary team must not be restricted to one part of the pathway and preference should be given to a team approach that follows the child across organisational boundaries from hospital to home.

Good communication between hospital and community professionals is essential and a working relationship between the acute sector, community providers and out of hospital transitional care centres is to be encouraged to offer the widest choice of out of hospital care for the child while the home care package is established.

For the older child (>13 yrs) links with Adult LTV services must be established and transition to adult services must be planned for.

4. Applicable Service Standards

4.1 Applicable national standards e.g. NICE

Applicable standards set out in Guidance and/or issued by a competent body (e.g. Royal Colleges)

- Services will adhere to the Service Standards produced by the West Midlands Quality Review Service
West Midlands Quality Review Service – Quality Standards – Services Providing LTV for Children and Young People (Dec 13 *under review) <http://www.wmqrs.nhs.uk/quality-standards/published-standards>
- The Royal College of Paediatrics and Child Health's Modelling the Future Report(s) of the Children and Young People's Health Outcomes Forum.
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216852/CYP-report.pdf
- Department of Health (2008) Commissioning Safe and Sustainable Paediatric Services: A

Framework of Critical Interdependencies

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_088068

- Department of Health (2006) Review of Commissioning Arrangements for Specialised Services (the Carter Review)
http://webarchive.nationalarchives.gov.uk/./+www.dh.gov.uk/en/Managingyourorganisation/Commissioning/Commissioningspecialisedservices/DH_4135174
- Department of Health (2006) Critical Care Minimum Data Set (CCMDS)
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_116368
- Department of Health (2003) Getting the Right Start: National Service Framework for Children; Standards for Hospital Services
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4006182
- Directorate (1997) Paediatric Intensive Care: “A Framework for the Future”
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4005760
- Healthcare Commission (2007) Improving Services for Children in Hospital
http://caredirectory.cqc.org.uk/db/documents/Improving_services_for_children_in_hospital.pdf
- Paediatric Intensive Care Society (2010) Standards for the Care of Critically Ill Children (v.2, 4th ed.) http://www.ukpics.org.uk/documents/PICS_standards.pdf
- Royal College of Nursing (2011) Health care service standards in caring for neonates, children and young people
http://www.rcn.org.uk/data/assets/pdf_file/0010/378091/003823.pdf
- Safeguarding children and young people-roles and competencies for health care staff. Intercollegiate document, September 2010. <http://www.rcpch.ac.uk/safeguarding>
- Protecting children and young people: responsibilities of all doctors. GMC Sept 2012. www.gmc-uk.org/guidance
- West Midlands Quality Review Service – Quality Standards – Services Providing LTV for Children and Young People (Dec 13 *under review)
<http://www.wmqrs.nhs.uk/quality-standards/published-standards>

5. Applicable quality requirements and CQUIN goals

5.1 Applicable quality requirements (See Schedule 4 Parts A-D)

Not applicable

5.2 Applicable CQUIN goals (See Schedule 4 Part E)

Not applicable

6. Location of Provider Premises

The Provider's Premises are located at:

To be completed by AT

7. Individual Service User Placement

Not applicable

ADOPTED

Appendix One

Quality standards specific to the service using the following template:

Quality Requirement	Threshold	Method of Measurement	Consequence of breach
Domain 1: Preventing people dying prematurely			
Providing parents/primary carers and immediate family a competency booklet/training programme facilitating safe care at home	To be agreed	Audit of practice/annual report	Non-compliance with contract General Conditions 8 & 9
Provision of Personal Care Plan with specific guidance on emergency management and escalation plans/community service links	To be agreed	Audit of practice/annual report	Non-compliance with contract General Conditions 8 & 9
Domain 2: Enhancing the quality of life of people with long-term conditions			
Follow up plan agreed before hospital discharge with clear plan for shared care	To be agreed	Audit of practice/annual report	Non-compliance with contract General Conditions 8 & 9
Annual patient clinical review, training updates for parents/carers and active assessment for ability to wean	To be agreed	Audit of practice/annual report	Non-compliance with contract General Conditions 8 & 9
Domain 3: Helping people to recover from episodes of ill-health or following injury			
Availability of a hospital key worker for liaison with child and family at least weekly	To be agreed	Audit of practice/annual report	Non-compliance with contract General Conditions 8 & 9
Availability of structured form of communication between MDT with team meetings held 4 weekly during the hospital stay	To be agreed	Audit of practice/annual report	Non-compliance with contract General Conditions 8 & 9

Quality Requirement	Threshold	Method of Measurement	Consequence of breach
Agreed managed hospital discharge pathway to facilitate care at home or closer to home	To be agreed	Audit of practice/annual report	Non-compliance with contract General Conditions 8 & 9
Domain 4: Ensuring that people have a positive experience of care			
Local patient satisfaction survey	To be agreed	Patient satisfaction results	Non-compliance with contract General Conditions 8 & 9
LTV team work in a networked way to share best practice	To be agreed	Evidence of network working	Non-compliance with contract General Conditions 8 & 9
Availability of parent/carers condition specific information when LTV needs are identified	To be agreed	Audit of practice/annual report	Non-compliance with contract General Conditions 8 & 9
Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm			
Shared best practice with a networked approach – diffusing expertise throughout the patient journey from hospital to home	To be agreed	Evidence of networking	Non-compliance with contract General Conditions 8 & 9
Access to LTV support/advice/information regardless of geographical location	To be agreed	To be agreed	Non-compliance with contract General Conditions 8 & 9
Compliance with national paediatric standards of care/NSF	To be agreed	Audit of practice	Non-compliance with contract General Conditions 8 & 9