

A14/S/a

**2013/14 NHS STANDARD CONTRACT  
FOR RESPIRATORY: COMPLEX HOME VENTILATION (ADULT)**

**PARTICULARS, SCHEDULE 2- THE SERVICES, A- SERVICE SPECIFICATIONS**

<b>Service Specification No.</b>	A14/S/a
<b>Service</b>	Respiratory: Complex Home Ventilation (Adult)
<b>Commissioner Lead</b>	
<b>Provider Lead</b>	
<b>Period</b>	12 months
<b>Date of Review</b>	

**1. Population Needs**

**1.1 National/local context and evidence base**

This specification relates to the tertiary hospital infrastructure necessary to enable the safe and sustainable establishment and maintenance of home care packages for patients with complex ventilation needs. This infrastructure includes:

- respiratory critical care with expertise in weaning patients to the least intrusive long-term ventilation modality necessary
- in-patient services to support the step down of intensive care unit (ITU) weaning patients
- assessment of new patients and care of established patients with acute or chronic deterioration
- diagnostic services for the assessment of patients with suspected complex ventilatory needs
- multi-disciplinary teams (MDTs) to provide holistic assessment of care for patients with multi-system disease (to include dedicated ventilation physicians, physiology technicians, physiotherapists, dieticians, speech and language therapy and occupational therapy)
- 24-hour emergency access to advice for local centres and to cover equipment failure.

The patient population served by this specialised service comprises tracheostomy-ventilated patients, individuals requiring diaphragm-pacing and those patients requiring sophisticated non-invasive ventilation. It is difficult to get accurate numbers of patients likely to benefit from this service in the absence of a national database.

There is likely to be considerable unmet need. Some figures that do exist include:

### **Weaning**

Modernisation Agency Critical Care Programme Survey, 2002. This was a snapshot survey of ITUs, carried out in England on one day. Thirty-four (22%) hospitals referred 73 patients to a specialist unit for weaning within a 12 month period. A total of 161 patients in 59% of the hospitals answering the survey fulfilled the criteria for weaning delay 85 (8%) or failure 76 (7%).

The North East & Cumbria Critical Care Network surveyed the incidence of weaning problems. Over a period of one year, a weekly telephone survey identified 161 stable patients with weaning delay (defined as patients ventilated for at least 6 hours per day for more than 2 weeks) in ITUs in the North of England. Twenty patients (12%) required more than 28 days of respiratory support. These patients occupied on average 6.0% of available intensive care unit beds in the region.

Data from Lane Fox Unit, London and Papworth Hospital, Cambridge suggests that complex home ventilation units transfer approximately 0.75 to 1.5 patients per million catchment population per month.

It is estimated that 1.5/million catchment population per month will require admission to a complex home ventilation unit because of weaning failure.

### **Complex Home Ventilation**

The Eurovent study (Eur Respir J 2005; 25; 1025-1031), reported a UK prevalence of 4.1 patients per 100,000 population receiving non invasive ventilation. The range for European countries was 0.1 (Poland) to 9.6 (Denmark - very well developed national service for patients with neuromuscular disease), average 6.6. These figures are likely to be a very significant underestimate of the situation now, based upon the reported year on year numbers of patients receiving non-invasive ventilation (NIV) in individual units.

The Danish data are likely to provide an accurate estimate of the numbers of adults with neuromuscular disease needing ventilatory support because they have a very well developed national service for patients with neuromuscular disease based exclusively in two university hospitals => 8 patients with complex neuromuscular disease needing NIV per 100,000 of general population. It is estimated that there will be 8/100,000 in the other categories needing complex ventilatory support.

### **Specialist Centres**

The overall aim of the specialist service is to establish and support patients with long-term breathing difficulties on the least intrusive ventilation modality possible. This will enable them to have a longer life of better quality than would otherwise be possible. Patients likely to need long-term support should be identified from at risk

groups (e.g. those with neuromuscular disease, severe scoliosis or chest wall deformity, morbid obesity or end stage respiratory disease causing hypercapnic respiratory failure) before that need becomes absolute. The aim should be to avoid admission to Intensive Care with respiratory failure through elective initiation of effective domiciliary ventilation. Whilst most of these patients will be identified by local services, periodic diagnostic assessment at specialist centres may be required.

A proportion of patients requiring long term ventilatory support present acutely, often via ITUs. Frequently these patients are difficult to wean from assisted ventilation and require domiciliary packages of care to be arranged prior to discharge. Prolonged weaning of individuals with chronic disease is a frequent cause of delayed discharge from ITU, blocks ITU beds and increases an individual's risk of morbidity and mortality. Specialist centres will provide advice, sometimes involving outreach, to critical care units within their region in the care of difficult-to-wean patients. In cases of very prolonged weaning, specialist centres will provide dedicated multi-disciplinary weaning services.

### **National Drivers**

Patients with complex chronic respiratory failure occupy intensive care beds inappropriately, resulting in bed pressures for acute admissions and cancelled major elective (particularly cancer) surgery.

This compromises the ability of trusts to meet four-hour emergency and 18 week treatment targets.

Patients discharged home or to a nursing home with inappropriately complex ventilatory care packages result in unnecessarily cumbersome and inappropriately expensive home care services being delivered.

This has major implications for healthcare budgets.

National Guidance for the provision of aspects of specialist non-ventilation services to patients exists for some individual patient groups e.g. Motor Neurone Disease (MND), Duchene's Muscular Dystrophy; for broader categories of patients e.g. weaning guidance; and around specific technologies e.g. diaphragmatic pacing and tracheostomies. There are some national standards available and some specialist society guidance. Provision of complex home ventilation services also falls within the NHS Outcomes Framework Domain 1 - preventing people from dying prematurely where Improvement Area 1a specifically identifies reducing mortality from respiratory disease, and Domain 2 – enhancing quality of life for patients with long term conditions.

Guidance supports delivery of care by respiratory specialists working within MDTs. For example, the National Institute for Health and Clinical Excellence (NICE) clinical guideline (CG) around use of NIV in MND states that “multidisciplinary teams (MDT) should coordinate and provide on-going management and treatment for patients with MND, including regular respiratory assessment and provision of non-invasive ventilation. The team should include a neurologist, a respiratory physician, an MND

specialist nurse, a respiratory specialist nurse, a specialist respiratory physiotherapist, a respiratory physiologist, a specialist in palliative care and a speech and language therapist". The guidance also outlines the support and training which need to be provided to the patient and their family and carers: "support and assistance to manage non-invasive ventilation which should include training on using non-invasive ventilation and ventilator interfaces, for example emergency procedures, night-time assistance if the patient is unable to use the equipment independently (for example, emergency removal or replacement of interfaces), how to use the equipment with a wheelchair or other mobility aids if required, what to do if the equipment fails, assistance with secretion management, information on general palliative strategies, an offer of on-going emotional and psychological support for the patient and their family and carers".

Ensuring NIV is delivered by competent respiratory professionals is emphasised in NICE MND guidance and also in the National Patient Safety Agency (NPSA) alert which identified cases where problems with administering NIV were stated as causing at least moderate harm: key issues included shortage of staff skills or staff time to set up and monitor NIV. Further recommendations are likely to result from the National Tracheostomy Safety Project.

The European Respiratory Society Consensus statement addresses models of care: "Acute care units probably lack the necessary focus, personnel and organisational structure to care for patients with prolonged weaning failure. In contrast, specialised weaning units (SWUs) offer specialised teams (e.g. nurses, physiologists, respiratory therapists, nutritionists, etc.) and an appropriate "bridge to home" environment for such patients and their families (e.g. privacy, daytime activity, longer visiting hours and undisturbed sleep). They also relieve pressure on scarce ITU beds. These units can be of two types: 1) step-down units or non-invasive respiratory care units within acute care hospitals, and 2) regional weaning centres that serve several acute care hospitals within the region. The type of unit preferable will depend on the healthcare structure and financing system of each individual region or country."

## **2. Scope**

### **2.1 Aims and objectives of service**

Chronic respiratory failure may arise due to a wide range of causes. This specification relates to patients with severe chronic respiratory failure requiring:

- Assisted invasive ventilation (partial and total dependency),
- Diaphragm pacing,
- Assisted non-invasive ventilation for more than 14 hours per day,
- Assisted non-invasive ventilation for less than 14 hours per day with significant co-morbidities that complicate the delivery of ventilatory support.

Specialist centres will provide a complete multidisciplinary assessment of the respiratory and medical needs of these patients and cover a number of broad groups of patients:

- Those who have been admitted to the intensive care unit who remain ventilator dependent after the acute illness has resolved. Support from the specialised service will be provided to try to get the patient on to the least invasive and least intensive level of ventilator support possible. End of life support for the patients who cannot be successfully weaned will also be provided.
- Individuals who are receiving overnight NIV who, because of disease progression, have become more dependent on ventilatory support whilst waking.
- Individuals with slowly progressive neuromuscular disease with associated respiratory failure (e.g. Duchenne muscular dystrophy, spinal muscular atrophy, Becker's muscular dystrophy, Limb Girdle Muscle Dystrophy) who have complex care requirements necessitating specialist multi-disciplinary input (e.g. neurology, gastroenterology, respiratory).
- Individuals transitioning from paediatric services.

The overall aim of the specialist service is to ensure equitable, consistent, cost effective assessment and long-term management of this vulnerable patient group.

The major objectives are :

- To provide a specialist multi-disciplinary service for diagnosis and treatment of complex ventilatory failure.
- To prevent premature death by ensuring equitable access to appropriate specialist treatment.
- To improve quality of life of both the patient and their carers.
- To maximise the possibility of patients being able to live in their own homes on the most appropriate and least invasive mode of ventilatory support with the maximum amount of time possible each day spent breathing spontaneously.
- To make it possible for patients with a high degree of ventilator dependency to live as normal a life as possible. This will be facilitated by maximising ventilator free time and optimising portable ventilatory support including portable or wheelchair mounted ventilators and cough assist.
- To improve outcomes for individuals failing to wean from invasive mechanical ventilation.
- To oversee those aspects of care that fall outside the expertise of local units.
- To reduce hospitalisations amongst individuals with complex respiratory failure.
- To ensure cost effective use of expensive resources.

The purpose of the service will be to:

- develop an equitable national complex home ventilation service whereby individuals with complex ventilator requirements will have access to specialist multi-disciplinary diagnosis, treatment and follow up.
- improve survival for individuals with chronic respiratory failure.
- maximise the possibility of individuals being discharged to their own home on the most appropriate and least invasive mode of ventilatory support; to make it possible for patients with a high degree of ventilator dependency to live as normal a life as possible; to address other aspects of the patient's care which

will be affected by the need for ventilatory support including nutritional support (e.g. gastrostomy feeding tube insertion), secretion clearance (e.g. cough assist device).

- deliver highly specialist, integrated multi-disciplinary care and provide clinical support to local centres, patients and their families.
- train family members, non-medical caregivers and carers, in the care of a ventilator-dependent patient.
- provide 24-hour access to nursing, medical and technical advice.
- reduce acute hospital admissions.
- develop and share national protocols and guidelines. Ensure local clinical teams are provided with management guidelines, and have access to specialist advice when needed.
- provide a national forum to discuss difficult management decisions. allow the most cost-effective use of intensive care unit beds.
- ensure that if the patient continues to deteriorate, the possibility of them dying in their preferred place of death, and providing effective palliative care, is maximised.

## **2.2 Service description/care pathway**

Currently the management and diagnosis of complex respiratory failure is directed by a number of guidelines (see section three). Specialised centres will interface with local and regional networks which together will deliver a holistic diagnostic and domiciliary ventilator service. It is anticipated that local units will maintain a diagnostic and treatment service for sleep disordered breathing and will be capable of managing simple nocturnal respiratory failure. Local centres will also be able to provide local surveillance monitoring of patients attending specialist centres.

Current coding is unable to reliably identify patients requiring specialist care.

Patients will be identified as those requiring referral from a local ventilation service, Respiratory Physician, or from a Consultant Intensivist for patients failing to wean on ITU, to the Specialist Centre. Patients will also be identified from databases held by Specialist Centres.

### **Specialist Centre (Complex Home Ventilation and Weaning Centre)**

Will provide diagnostic and multi-disciplinary assessment and management of all patients requiring complex home ventilation. Each Complex Home Ventilation and Weaning centre will serve a population of approximately 5 million. The centres will provide inpatient weaning facilities, and outpatient or day case multi-disciplinary assessment and treatment services.

### **Complex Inpatient Ventilation**

Patients requiring inpatient specialist services will be those failing to wean from invasive ventilation on ITU (usually following an acute respiratory illness on a background of chronic ventilator impairment) or those newly requiring > 14 hours

NIV per day following an acute hospitalisation on a background of chronic respiratory failure.

Service entry criteria are those provided by the NHS Modernisation Agency Critical Care Programme Weaning & Long Term Ventilation definition):

*Weaning Delay* - 2 week attempt to wean patient from invasive ventilation should prompt a referral from ITU to a weaning unit. Specialist centres will be expected to provide advice and, where appropriate, outreach to help local services develop appropriate weaning plans for patients identified with weaning delay. Patients at this stage may either:

- Improve – in which case they will be transferred to local respiratory services
- Fail to improve – in which case they will be classified as a weaning failure

*Weaning Failure* - 3 week attempt to wean patient from ventilation. These patients will be referred to the specialist centre most geographically convenient for them and their family/carers.

Individuals transferred to specialist centres will undergo full multi-disciplinary assessment. Where appropriate this will include appropriate pulmonary and cardiac imaging, assessment of respiratory muscle function and swallowing and nutritional assessment.

- Where appropriate patients will be tracheostomised.
- Multi-disciplinary decisions will be made as to whether the patient can be weaned from invasive ventilatory support to non-invasive ventilation or even weaned fully from ventilation
- A small proportion of these patients may, at some stage, be weaned from all ventilatory support, e.g. those with a critical care neuropathy/myopathy in which a degree of recovery is expected or those with a neuromuscular condition which reverses with treatment (e.g. Guillain Barre Syndrome, polymyositis).
- For the majority of these patients some form of life-long ventilatory support will be required.
- Appropriate neurological and cardio-respiratory rehabilitation will be provided as part of the weaning process.

### **Service Exit Criteria for Inpatient Ventilation**

- Patient weaned requiring no ventilatory support at the time of hospital discharge
- Patient weaned to night time NIV only - care to be shared with local services (estimate 20%) or patients need to be continued to be managed long term by Complex Home Ventilation and Weaning Centre
- Patient weaned to more than 14 hrs/ day NIV to be managed long term by Complex Home Ventilation and Weaning Centre
- Patient requires continued tracheostomy ventilation to be managed long term by Complex Home Ventilation and Weaning Centre
- Patient requiring less than 14 hours/day NIV but with complex co-morbidities

- Patient dies: requires palliative ventilation and the opportunity, when desired to die at home.

Referrals will be from Consultant Intensivists direct to Complex Home Ventilation and Weaning Centre. It is advised that they should discuss the patient with either their trust ventilatory lead or a Consultant in Assisted Ventilation from their neighbouring Home Ventilation Unit or a Consultant at the Complex Home Ventilation and Weaning Centre at 7 days (after acute illness treated) of difficulty to wean; by day 14 refer to Complex Home Ventilation and Weaning Centre, who may visit the patient in the referring unit, and at approx day 21 transfer to the Complex Home Ventilation and Weaning centre.

### **Complex Home Ventilation**

Outpatient or day case multi-disciplinary assessment will be provided at specialist centres for the following groups of patients:

- Tracheostomy ventilated
- More than 14 hours/day non-invasive ventilator dependent
- Less than 14 hours/day non-invasive ventilator dependent patient with associated complex medical diagnoses (e.g. neuromuscular disease, cardiomyopathy, morbid obesity awaiting bariatric surgery) needing other specialist input and / or complex home care package.
- Diaphragm pacing
- Patients with sub-optimal control of sleep disordered breathing
- Those transitioning from paediatric services

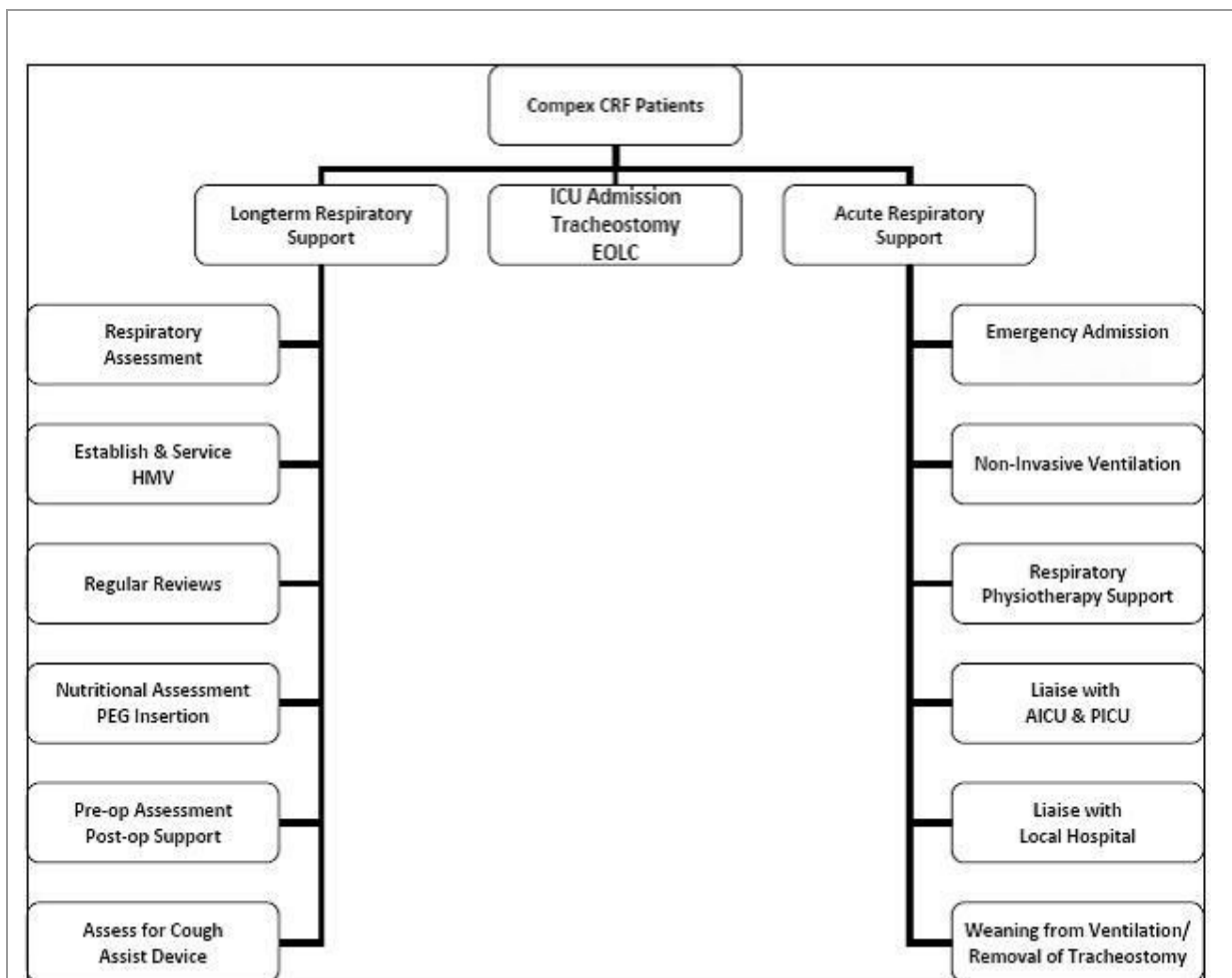
### **Service Entry Criteria**

Patients will be referred from local non-invasive ventilation units if they fall into one of the above groups. Certain patients may be referred directly as part of other care pathways e.g. (a) Duchenne muscular dystrophy patients transitioning from paediatric care (b) Duchenne muscular dystrophy patients referred for spinal surgery (c) young neurological patients referred with suspected sleep disordered breathing (d) congenital heart disease patient referred with suspected sleep disordered breathing (e) bariatric surgical patients referred with suspected chronic respiratory failure.

### **Service Exit Criteria**

Patients will usually need to remain under the Complex Home Ventilation and Weaning Centre indefinitely. A small proportion (less than 10%) of patients (e.g. those with ITU acquired weakness) who are initially discharged home with a high degree of ventilator dependency may become less dependent over time. Once they no longer fulfil the criteria for the Complex Home Ventilation and Weaning Centre, they can be stepped down to a local NIV unit. The majority ( more than 90%) of patients, however, will require lifelong support, review and annual reassessment by the Complex Home Ventilation and Weaning Centre.





- Patients with sub-optimal control of sleep disordered breathing of whatever aetiology will be discharged back to the local NIV unit when ventilatory support has been optimised.
- Some patients needing nocturnal ventilation and having complex medical diagnoses needing other specialist input may be transferred back to the local non-invasive ventilation unit (LNVU) when there is no ongoing need for other specialist input.

*Abbreviations: CRF = Chronic Respiratory Failure; ITU = intensive care unit; HMV = home mechanical ventilation; PEG = percutaneous gastrostomy feeding tube; AITU/PICU = adult/paediatric intensive care unit; EOLC = End of life care*

### **Infrastructure and Multidisciplinary Team for Complex Home Ventilation and Weaning Centre**

- In patient weaning beds should be staffed at a ratio of one nurse to 2 patients (NHS Modernisation Agency recommendation for staffing of a high dependency unit -- compared with 1 to 1 on an ITU).
- At least two consultants with expertise in respiratory physiology, weaning and complex ventilation to provide daily ward reviews.
- 24/7 specialist consultant on call cover.

- 24/7 resident specialist respiratory or critical care registrar with direct responsibility for the unit.
- 24/7 helpline for patients.
- Rapid access to inpatient services.
- Specialist respiratory and rehabilitation physiotherapist.
- Speech and language therapist.
- Occupational therapist.
- Clinical psychologist.
- Dietician.
- Clinical nurse specialist/physiotherapist/physiologists to support ventilated patients at home.
- In-house technical support (or outsourced) for servicing and maintenance of home ventilators.

### 2.3 Population covered

The service outlined in this specification is for patients ordinarily resident in England\*; or otherwise the commissioning responsibility of the NHS in England (as defined in '*Who Pays?: Establishing the responsible commissioner*' and other Department of Health guidance relating to patients entitled to NHS care or exempt from charges).

\* Note: for the purposes of commissioning health services, this EXCLUDES patients who, whilst resident in England, are registered with a GP practice in Wales, but INCLUDES patients resident in Wales who are registered with a GP practice in England.

Specifically individuals to be assessed at specialist centres will fulfil the following criteria:

Complex Inpatient Ventilation.

- NHS Modernisation Agency Critical Care Programme Weaning & Long Term Ventilation definition):
  - Weaning Delay - 2 week attempt to wean patient from invasive ventilation should prompt a referral from ITU to a weaning unit. Patient reviewed by Complex Home Ventilation and Weaning Centre outreach team and advice given.
  - Weaning Failure - 3 week attempt to wean patient from ventilation - transfer to Complex Home Ventilation and Weaning Centre.

Complex Home Ventilation.

- Tracheostomy ventilated.
- More than 14 hours/day non-invasive ventilator dependent patient
- Less than 14 hours/day non-invasive ventilator dependent patient with associated complex medical diagnoses (e.g. neuromuscular disease, cardiomyopathy, morbid obesity awaiting bariatric surgery) needing other specialist input and / or complex home care package.
- Diaphragm pacing.

- Patients with sub-optimal control of sleep disordered breathing.
- Those transitioning from paediatric services.

## 2.4 Any acceptance and exclusion criteria

### Referral sources:

- Intensive care units
- Local ventilation units or sleep services
- Consultant Respiratory Physicians
- Consultant Neurologists
- Transition patients from paediatric ventilations services

### Acceptance criteria:

- Patients on ITU fulfilling the definition of failure to wean
- All tracheostomy ventilated patients
- Individuals suspected to require diaphragm pacing
- Individuals with chronic respiratory failure likely to require more than 14 hours per day NIV
- Patients with multi-system progressive disease needing multidisciplinary assessment of ventilator requirements.
- Patients with progressive neuromuscular disease suspected to require NIV
- Patients transitioning from specialist paediatric services

### Exclusion criteria:

- This specification does not cover paediatric patients
- Uncomplicated sleep disordered breathing
- Nocturnal respiratory failure requiring less than 14 hours NIV support per 24 hours.
- Individuals with high cervical spine injuries. The provision of ventilator support for these individuals is addressed by the Spinal Injuries CRG service specification.
- Patients for whom long term ventilation is not in their best interests on the grounds of futility (for example very poor limited prognosis due to associated or underlying disease severity). This should usually only be after the case has been discussed with the Complex Home Ventilation and Weaning Centre.
- Respiratory care for patients with high spinal cord injuries is covered in the service specification for spinal cord injuries

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

## 2.5 Interdependencies with other services

### **Co-located services**

- ITU,
- physiotherapy,
- speech and language,
- dietetics,
- occupational therapy
- sleep diagnostics,
- radiology.

### **Interdependent services**

- neurology/neurosciences,
- palliative care.

### **Related services**

- ITUs in the local Critical Care Networks,
- neurorehabilitation (medical, physiotherapy and occupational therapy),
- gastroenterology (gastrostomy feeding tube insertion for progressive NMD),
- cardiology (for inherited slow progressive NMD),
- surgery (spinal, ear nose and throat (ENT) and urology),
- Morbid obesity services,
- Local sleep services and ventilation units.

## 3. Applicable Service Standards

### 3.1 Applicable national standards e.g. NICE, Royal College

#### **National and International Guidance**

NHS Modernisation Agency Critical Care Programme - Weaning and Long Term Ventilation 2002

*'Motor neurone disease: the use of non-invasive ventilation in the management of motor neurone disease'* NICE clinical guideline 105, 2011

Respiratory Care of the Patient with Duchenne Muscular Dystrophy

American Thoracic Society (ATS) Consensus Statement, March 2004

NICE Interventional Procedure Guidance (IPG)307 *Intramuscular diaphragm*

*stimulation for ventilator dependent chronic respiratory failure due to neurological*

*disease: guidance 2009*

NICE quality standard for Chronic Obstructive Pulmonary Disorder, standard 11: relates to provision for NIV. 2011

Non-invasive ventilation in chronic obstructive pulmonary disorder: management of acute type 2 respiratory failure - Royal College of Physicians/British Thoracic Society concise guideline, 2008

Intensive care society: Weaning guidelines 2007

National Patient Safety Agency (NPSA) Difficult airway society, Intensive care society National Tracheostomy Safety Project currently underway: guideline development

NPSA Signal: non-invasive ventilation 2011

European Respiratory Society Task force Weaning from mechanical ventilation. Eur Respir J 2007; 29: 1033–1056. Statement of the Sixth International Consensus Conference on Intensive Care Medicine Organised jointly by the European Respiratory Society (ERS), the American Thoracic Society (ATS), the European Society of Intensive Care Medicine (ESICM), the Society of Critical Care Medicine (SCCM) and the Societe de Reanimation de Langue Francaise (SRLF), 2007

## **Service Standards**

### Core Standards

- In patient weaning beds.
- At least two consultants with expertise in respiratory physiology, weaning and complex ventilation.
- 24/7 specialist consultant on call cover.
- 24/7 resident specialist respiratory or critical care registrar with direct responsibility for the Unit.
- 24/7 helpline for patients.
- On site ITU.
- Specialist respiratory and rehabilitation physiotherapist.
- Speech and language therapist.
- Occupational therapist.
- Clinical psychologist.
- Dietetics.
- Clinical nurse specialists/physiotherapists/physiologists to support ventilated patients at home.
- Outreach service,
  - ITUs,
  - Home visits for very dependant patients.

- In-house technical support (or outsourced) for servicing and maintenance of home ventilators.
- Pulmonary physiology including ability to measure lung function, muscle strength and sleep studies.
- Able to undertake bronchoscopy.
- Able to provide diaphragm pacing.
- Clearly defined pathways of care with LVNUs.
- Dedicated links with,
  - Paediatric services,
  - Neuromuscular networks,
  - Palliative care services,
  - Neurorehabilitation services,
  - Cardiology,
  - Spinal surgery,
  - ENT,
  - Percutaneous nutrition service,
  - Morbid obesity services.

#### Recommended Standards

- Integrated clinical trials unit (linked with Comprehensive Local Research Networks) offering patients the opportunity to participate in clinical trials.
- A national registry, collecting core outcome, data.

#### Databases

Databases of complex home ventilation patients are often held at a local level by units providing this service, but these are not standardised in terms of the information held, and do not provide a comprehensive picture of national provision.

Consideration would need to be given to database formation and maintenance with necessary technical expertise. Ideally, there should be a national registry. As a starting point providers will be expected to provide a patient list on a monthly basis

### 4. Key Service Outcomes

The following data will be collected annually to monitor clinical outcomes:

#### Weaning:

- Weaning outcomes (needs to be adjusted for case mix) - discharge home, nursing home, hospital, death.
- Weaning rates - fully weaned, NIV overnight, tracheostomy ventilation and death).
- Hospital and ITU length of stay during index weaning episode.
- 28 day readmission rate.

**Patients receiving home mechanical ventilation:**

- Arterial blood gas tensions.
- Health related quality of life, disease-specific and generic.
- Physical and functional scores.
- Carer quality of life.
- Mortality data.
- Hospitalisations.

Interim for Adoption from 01/10/13