

Critical Care Programme
Weaning and long term ventilation



Foreword

Comprehensive Critical Care, the Report of an Expert Group to the Department of Health, was published in 2000. It outlined a far-reaching modernisation programme for the development of critical care services around a new approach based upon the severity of illness. In presenting the Report the Expert Group identified several issues impacting directly upon the level of critical care support within NHS Trusts which would require additional, detailed evaluation. One such area related to the needs of patients with acute and chronic respiratory insufficiency, including specialist weaning, long term ventilation and the use of non-invasive ventilatory support.

The working group of experts set up to review these issues began by defining terms such as ventilatory dependence (acute and chronic) and weaning (delayed or failed). Secondly, the group evaluated the existing literature regarding 'best practice' to address the issues, where possible, in an evidence-based fashion. Thirdly, an assessment of the nature and size of the diagnostic groups was made, which ranged from the relatively common (eg COPD) to the clinical disorders requiring highly specialised evaluation and management (eg muscular dystrophies, spinal injuries). Fourthly, the way in which such services (where present currently) have evolved was considered in order to assess their place in the context of a comprehensive critical care service. Optimal staffing and their training needs, and the best way of auditing any services were debated. Finally, where epidemiological data were unavailable for England, specifically relating to the evidence of delayed or failed weaning, a survey was undertaken which provided invaluable information.

The recommendations of the working group contained in this report are a significant further contribution to the modernisation of critical care services which is currently underway. The report identifies many ways that patient care can be improved and demonstrates the cost effectiveness of improved care. Commissioners and Critical Care Networks should review how the needs of these patients are being met and develop services in line with the recommendations set out in the report.

Thanks are due to the members of the group, who gave freely of their time and expertise to produce this report, and especially to Professor Tim Evans, their Chairman.

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1.0 Introduction to the Working Group in the context of the document ‘Comprehensive Critical Care’

- 1.1 In 1999 the Department of Health established a review of adult critical care services and invited an expert group, comprised of experienced practitioners from relevant professional bodies, to develop a framework for the future organisation and delivery of critical care.
- 1.2 The report of the group, entitled Comprehensive Critical Care and published in 2000 (1), outlined a far reaching modernisation programme for the development of critical care services around a new approach based upon the severity of illness.
- 1.3 It was proposed that critical care services should be planned and delivered systematically across the whole health system. Thus, the existing division of beds into high dependency, intensive care and “ordinary ward” categories would be replaced by a classification focussing on the level of care required by individual patients, which would in turn determine the need for staff, in terms of numbers, skills and expertise.
- 1.4 The service would be *integrated* into a hospital-wide approach extending beyond the physical boundaries of Intensive Care (ICU) and High Dependency Units (HDU), thereby making optimum use of available resources. Secondly, the service would transcend individual NHS Trusts, working to common standards and protocols, and taking responsibility for all critically ill patients in all specialities within a geographical area. Thirdly, a planned approach to workforce development was proposed. This was to include the recruitment, training and retention of medical and nursing staff. A balanced skill-mix should also be encouraged enabling delegation of less skilled and non-clinical tasks. Finally, the new service would be underpinned by reliable information. Comparative audit and a culture of data collection should ensure the delivery of effective clinical care.
- 1.5 Critical care would therefore be provided within a continuum of primary, secondary and tertiary care. The new classification of individual patient dependency was:
 - 1.5.1 Level 0: Patients whose needs can be met through normal ward care in an acute hospital
 - 1.5.2 Level 1: Patients at risk of their condition deteriorating or those recently relocated from higher levels of care, whose needs can be met on an acute ward with additional advice and support from the critical care team
 - 1.5.3 Level 2: Patients requiring more detailed observation or intervention, including support for a single failing organ system or post-operative care, and those stepping down from higher levels of care
 - 1.5.4 Level 3: Patients requiring advanced respiratory support alone or basic respiratory support, together with the support of at least two organ systems. This level to include all complex patients requiring support for multi-organ failure

2.0 Implementation of ‘Comprehensive Critical Care’

- 2.1 The NHS Modernisation Agency Critical Care Programme was established following the publication of ‘Comprehensive Critical Care’ to implement the modernisation programme.
- 2.2 The Critical Care Programme is predicated on the principle of ensuring improved patient outcome whilst maximising efficiency and service delivery, so that increased capacity is not alone used to meet increased demand. The programme has three main components:
 - 2.2.1 A critical care collaborative programme
 - 2.2.2 A programme of visiting
 - 2.2.3 Analytical work which will provide further advice on the appropriate size and configuration of the service

- 2.3 The implementation of the NHS Modernisation Agency Critical Care Programme is overseen by a programme advisory group, the primary function of which is to advise and support the work of the NHS Modernisation Agency Critical Care Team.
- 2.4 Within the overall integrated approach to Critical Care, there are a number of clinical conditions impacting directly upon the level of critical care support required within Trusts that may require additional evaluation. The following groups of patients were identified for further detailed review:
 - 2.4.1 Those patients requiring specialist weaning and progressive care for long term ventilation. In 'Comprehensive Critical Care', NHS Trusts were recommended to review the need for the provision of these services for those patients likely to benefit.
 - 2.4.2 Those patients in whom non-invasive ventilatory (NIV) support may prove to be equally efficacious in averting progression towards respiratory failure, or in supporting those patients with specific types of respiratory insufficiency, thereby obviating their need for intensive care.
 - 2.4.3 Those patients in whom chronic or terminal illness with little or no acute reversibility might be afforded non-invasive ventilatory support in a palliative or supportive sense, again avoiding the need for escalation to higher levels of dependency.

3.0 History and development of non invasive positive pressure ventilation (NIV)

- 3.1 Until the late 1970s the only forms of ventilation suitable for long term use were those administered through a (permanent) tracheostomy, or using negative pressure ventilation applied via a tank ventilator, cuirass or jacket/poncho ventilators. These latter devices were used extensively in the 1940s and 50s during epidemics of poliomyelitis, but were unsuitable for bulbar polio victims and those with extreme ventilator dependency.
- 3.2 The successful application of nasal continuous positive pressure ventilation (CPAP) in patients with sleep apnoea was first reported in the early 1980s (2). It was the extension of this approach to patients with chronic ventilatory insufficiency (initially secondary to neuromuscular and chest wall disease), combined with improved mask design, that led to the pioneering work of Brochard and others (3,4) in applying NIV in the ITU for patients with chronic obstructive pulmonary disease (COPD) suffering acute (hypercapnic) exacerbations. Subsequent studies have confirmed the effectiveness of NIV in other groups with non COPD acute respiratory failure and for weaning (5,6).
- 3.3 In chronic respiratory failure domiciliary NIV is now the treatment of choice in patients with neuromuscular and chest wall disease (7). Recent literature also suggests that within the ICU, NIV (*vide infra*) can reduce the need for intubation and reduce mortality associated with severe episodes of chronic pulmonary disease.
- 3.4 Data concerning the use of NIV in acute respiratory failure are more robust. Thus, an International Consensus Conference in Intensive Care Medicine evaluating the use of non invasive positive pressure ventilatory support in patients with acute respiratory failure considered the following questions, and provided detailed evaluation of the evidence (8):
 - 3.4.1 What are the rationale, potential benefits and goals for NIV?
 - 3.4.2 What equipment and which modes of ventilation should be used?
 - 3.4.3 Who should administer NIV and in which location?
 - 3.4.4 What are the indications for NIV in patients with ARF?
 - 3.4.5 What are the other indications for NIV in the acute care setting (e.g. weaning, avoidance of intubation, peri-operatively)?

- 3.5 In early studies across diagnostic groups, volume preset ventilators have predominated, but latterly these have been largely superseded by pressure preset ventilators, including machines delivering bilevel pressure support, for both hospital and home use.
- 3.6 In view of these developments, the NHS Modernisation Agency's Critical Care Team assembled a sub-committee to consider specifically within the terms of reference set out below, the place of NIV in the provision of critical care.

4.0 Terms of reference of the subgroup on weaning and long term ventilation

- 4.1 The subgroup was designed as a forum for multi-professional experts to discuss the issues related to current practice in these areas and the resources needed to deliver the service. The sub-group was also expected to advise on perceived future needs and how these can be met. The specific aims and terms of reference of the sub-group were:
- 4.1.1 To identify the types of patient (by diagnosis) that may present with problems in weaning or that require long term ventilation
 - 4.1.2 To assess what the current demands on the service are related to the different types of patient identified in 2.4.1 - 2.4.3
 - 4.1.3 To assess the current capacity available to meet the demand in these clinical arenas
 - 4.1.4 To assess the resources currently available to deliver the service in terms of facilities, staffing levels, equipment, training
 - 4.1.5 To review current practice relating to the care of these patients
 - 4.1.6 To define what is considered best practice and to identify 'gaps' between this and current practice
 - 4.1.7 To ensure the review of services and advice given reflects the needs for multi-professional working
 - 4.1.8 To ensure that any recommendations are patient focused and consider the views of the user and carers

4.2 Membership of the group was:

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Royal Victoria Infirmary, Newcastle

Dr. A.C. Davidson, Consultant in Intensive Care and Respiratory Support,
Guy's & St Thomas' Hospital, London

Dr. M. Elliott, Consultant Physician,
St James's University Hospital, Leeds

Professor T. W. Evans (Chairman), Professor of Intensive Care Medicine,
Royal Brompton Hospital, London

Ms D. Field, Specialist Respiratory Weaning Nurse,
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Ms. S. Keilty, Superintendent Physiotherapist,
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Dr. A. Simonds, Consultant Physician,
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Ms. M. Spencer, National Clinical Lead - Nursing and Allied Health Professionals,
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Dr. J. Watt, Consultant Anaesthetist,
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5.0 Definitions and glossary of terms employed by the sub group

- 5.1 Ventilatory dependence: The need for ventilatory support applied either invasively or non-invasively in order to prevent or treat respiratory failure.
- 5.2 Weaning: The process of becoming independent from ventilatory support.
- 5.3 A wide range of criteria have been used to define ventilatory dependence and weaning. The following were adopted for use by the Committee:
- 5.3.1 Acute ventilatory dependence: Patients dependent upon all forms of ventilation, such as assist control and pressure support ventilation, negative pressure ventilation and CPAP. In the acute setting, invasive ventilation applied using a nasal or oral endotracheal tube, or a tracheostomy is common, but face or nasal mask ventilation is increasingly used. A minimum requirement of six hours per day has been taken as defining ventilatory dependence. The need for ventilatory support for more than two weeks in the absence of any non-respiratory factor preventing weaning has been used to define 'weaning delay'. If this persists for three weeks it is termed 'weaning failure'. These durations are not necessarily the same as the length of stay in critical care areas, since co-existing multi-system failure may prevent weaning. The location of the patient in a critical care area is not a prerequisite for being ventilator-dependent.
- 5.3.2 Chronic ventilatory dependence: This includes dependence upon all forms of positive and negative pressure ventilation, but CPAP provided by a nasal or face mask is excluded. Ventilation may be provided either invasively or non-invasively, but the retention of a tracheostomy without any mechanical ventilatory support is not regarded as inferring ventilatory dependence. Patients who require ventilatory support regularly each day or night, irrespective of how many hours it is used for, are deemed to be ventilatory dependent if the duration of treatment exceeds one month. Ventilatory support is usually received in the home rather than hospital. The weaning process ceases when the patient's condition is stable, medical treatment has been optimized and the requirements for ventilatory support minimized.

6.0 NIV as a means of preventing Level 3 admission in the acutely ill

- 6.1 Nature of the patient groups: COPD
- 6.1.1 An acute exacerbation of COPD is a common reason for hospitalisation. Moreover, an exacerbation of sufficient severity to necessitate hospital admission is associated with a poor prognosis (6 to 26% mortality) (9,10). In one study an in-hospital mortality of 11% was reported but this increased over the next 2 months, 6 months, 1 year and 2 years of follow up to 20%, 33%, 43% and 49% respectively (11). A second study identified 5 year survival rates of 45% after hospital discharge, but this decreased to 28% with any further episode of hospitalisation (12).
- 6.1.2 NIV has been shown to reduce the need for intubation (ETI). In larger studies (4,13) NIV improved the survival of patients presenting to hospital in acute respiratory failure. The avoidance of complications of ETI, particularly nosocomial infection, an important cause of morbidity, mortality and prolonged ICU stay, is a feature of many of these studies (14). It is more likely to be effective when introduced earlier than would normally be the case for intubation and MV (13,15). Current data suggest that 3 patients need to receive NIV to prevent one intubation.
- 6.1.3 Although admissions to Level 3 for acute exacerbations of COPD have been low in the UK historically, this is likely to change as patients are increasingly involved in clinical decision-making processes, particularly as these relate to resuscitation.

6.2 Nature of the patient groups: other conditions

- 6.2.1 Most studies have considered the benefits of administering NIV to patients with COPD. However, recent studies have focused on other patient groups, mainly with acute respiratory failure (5,16,17).
- 6.2.2 These indicate that NIV is more likely to be of benefit when introduced early (5,13,17). They confirm that a trial of NIV does not result in a worse outcome compared to patients intubated from the outset. If successful, NIV reduces duration of ICU and hospital stay (16,18).
- 6.2.3 In patients with haematological malignancy, who have a very poor prognosis if intubated, NIV improves outcome (17).
- 6.2.4 NIV reduces complication rates, particularly those related to infection (14,16,17).
- 6.2.5 NIV should be seen as complementary to ETI and mechanical ventilation, whereby intubation and its attendant complications can be avoided in selected patients.

6.3 Location of provision of service

- 6.3.1 A large UK (YONIV) study indicated that NIV can be applied successfully outside the ICU/HDU setting, but that outcome for patients with a pH < 7.30 was not as good as that seen for comparable patients studied in a higher dependency setting (13). Outside the ICU, NIV was a highly cost-effective option, the savings coming exclusively from preventing ICU admission (19).
- 6.3.2 Training, patient throughput and skill retention are optimised if NIV is performed in a mixed sex location where patients with Level 1-2 dependency can be managed. Modelling the variability in monthly use of NIV using the Poisson distribution for different settings has shown that if all patients are managed in one location, the percentage of months in which one or fewer patients are treated is 1.7%, compared to 20% if two locations are used (20). This has implications for nursing staff skill retention. Currently, there are few such Units in the UK and NIV is performed predominantly on General/Respiratory wards (40%), followed by HDUs (12%), ICUs (13%) or a combination of these. However at the time of this (1998) survey, only 48% of hospitals provided an acute NIV service, often funded through research or charitable funds (21).
- 6.3.3 Respiratory units providing care to patients with levels of dependency between 0 and 3 can be clinically and cost effective (22). A study (23) of 756 consecutive patients admitted to 26 respiratory intermediate care units in Italy with a nurse to patient ratio ranging from 1:2.5 to 1:4 per shift, and availability of adequate continuous non-invasive monitoring, showed a better outcome than expected on the basis of Apache II severity of illness scores. Thus, predicted inpatient mortality risk rate was 22.1% but actual mortality rate was 16%. The highest proportion of patients (47%) were admitted from emergency departments; with 19% from other medical wards, 18% transferred from the ICU, 13% from specialist respiratory wards and 2% following surgery. All but 32 patients were in respiratory failure at admission. The reasons for admission were for monitoring due to clinical instability (n=221), mechanical ventilation (n=473) and weaning (n=59). Some 586 patients required mechanical ventilation during their stay; 425 using non-invasive techniques initially (374 by non-invasive positive pressure, 51 by iron lung). 161 underwent invasive mechanical ventilation (63 intubated, 98 tracheostomies). All but 48 patients had chronic respiratory disease, mainly COPD (n=451). It should be appreciated that a proportion needed invasive mechanical ventilation, and in the UK these would be admitted to a level 3 facility, but the majority were managed using non-invasive techniques performed in alternative locations.

- 6.3.4 There are few data concerning the potential number of patients needing NIV acutely. A one year period prevalence study from Yorkshire (20) estimated that an average DGH (SMR for COPD 100, catchment area 250,000) would expect to ventilate 6 patients per month. This included only patients admitted with COPD and an acute exacerbation fulfilling the blood gas criteria for NIV and not those who deteriorated subsequently or with respiratory failure of other causes. Experience from a Leeds Teaching Hospital (catchment population of approx 325,000) suggests that the provision of six beds for patients with ventilatory insufficiency due to respiratory disease, and to provide a step down facility from Level 3 dependency, is reasonable, but excludes the provision of support for patients with more complex and prolonged weaning needs. For a DGH serving 250,000 a four bedded Unit is likely to suffice.

Acute Respiratory Care Units established at St James's University Hospital and Leeds General Infirmary

Each Unit admits approximately 300 patients per year each with acute exacerbations of COPD and other conditions needing non invasive ventilation, patients with acute respiratory disease such as pneumonia and asthma fulfilling severity criteria requiring monitoring, and patients from Intensive Care with weaning delay or failure. The Units are multidisciplinary serving as a focus for nurses with particular experience and expertise in acute respiratory disease, tracheostomy care and non invasive ventilation, and for specialist Respiratory Physiotherapists. There are clearly defined admission criteria and close working relationships with the Accident and Emergency Departments and Intensive Care Units. For further information contact Dr Mark Elliott, Consultant Respiratory Physician, St James's University Hospital, Leeds. Tel 0113 206 6037 Fax 0113 206 6042 Markw.elliott@leedsth.nhs.uk

7.0 NIV in the support of patients with chronic respiratory insufficiency

7.1 Patients with neuromuscular/chest wall disease

- 7.1.1 Long term ventilation has been used for decades in patients with chronic ventilatory failure due to neuromuscular (e.g. previous poliomyelitis, muscular dystrophies and myopathies) and chest wall (e.g. due to scoliosis or thoracoplasty) diseases. The introduction of ventilatory support improves quality of life and reduces morbidity. There are no randomised controlled trials in these patient groups but as the introduction of ventilatory support is life-saving, these studies would be unethical. Unless there is marked bulbar weakness or extreme ventilator dependency, non-invasive modes should be used. These patients are best managed by centres specialising in long term home ventilation.
- 7.1.2 There is no evidence as yet to support long term non-invasive ventilation in patients with ventilatory failure due to COPD, although it is possible that certain subgroups may benefit.

Prevention of Level 3 admission in patients with chronic disorders

Royal Brompton and Harefield NHS Trust runs a Respiratory Support Service for individuals with respiratory insufficiency due to neuromuscular disease, chest wall disorders and COPD. This service is one of at least three in the UK (including Papworth Hospital, Cambridge and St Thomas' Hospital, London) which care for over 500 such individuals. Patients have access to acute admissions for NIV, home visits, and a 24 hour hotline for medical and equipment advice. Prompt introduction of NIV, or intensive NIV in patients already dependent on ventilatory support, can reduce the severity and frequency of infective respiratory episodes and allow patients to be cared for in level 1 & 2 beds.

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7.2 Patients with chronic lung disease

7.2.1 There is no evidence as yet to support the use of long term domiciliary NIV in patients with chronic hypercapnic respiratory failure due to COPD; although there are some data showing benefit in certain sub groups.

7.2.2 NIV has a role in 'bridging' patients with chronic respiratory failure to lung transplantation.

7.3 Patients with spinal cord injury

7.3.1 The rate of acute respiratory insufficiency following acute spinal cord injury (ASCI) is of the order of one per million of the population per annum, and of those about one quarter may remain long term ventilator-dependent (LTVD). Patients with ASCI constitute between 5 and 20% of these and have some clinical features in common with neuromuscular weakness, such as well preserved pulmonary function.

7.3.2 ASCI is distinct in its acute onset, the multi-system nature of the disorder, the high level of dependency and the non-progressive nature of the condition.

7.3.3 There is a higher rate of complications in spinal cord injury patients treated outside the 12 UK specialist centres. Early referral is encouraged, although the ability of centres to admit patients with high cord lesions acutely is compromised by an inability to discharge those who remain ventilator-dependent. Consequently, many centres have already developed a programme for domiciliary ventilation despite the absence of national service provision or appropriate training infrastructure. Although general principles outlined elsewhere in this report apply, features of any proposed service specific to the requirements of patients with spinal cord injuries would need to be addressed.

7.3.4 The need for ventilatory support in acute tetraplegia may be avoided in some cases by regular chest physiotherapy and pulmonary expansion sessions using intermittent positive pressure breathing. Most practitioners regard it as inappropriate to support respiration in the presence of frank respiratory failure using non-invasive means. Surgical tracheostomy is preferred to the percutaneous approach because of cervical spine injury.

7.3.5 Young to middle-aged persons with neurological lesions below the mid cervical level usually wean successfully (average 30 days). Faster weaning of tetraplegic patients is achieved when large tidal volumes are applied in conjunction with graded periods of abstinence from the ventilator (24).

- 7.3.6 The safety of non-invasive support in apnoeic tetraplegic patients compared to that applied via a tracheostomy has not been evaluated. Tetraplegic patients with appropriate management of their tracheostomy frequently express a preference for this compared to NIV administered using a face mask. Appropriate tracheal tubes should be selected without cuffs but there need to be adequate monitoring procedures especially during sleep, in conjunction with the appropriate ventilatory apparatus (25,26).
- 7.3.7 Selected patients with high tetraplegia benefit from diaphragmatic pacing offered by a small number of centres (27). Successful discharge and follow up is a multi-professional discipline (28).
- 7.3.8 The incidence of sleep disordered breathing in tetraplegic persons is 2 -5 times greater than the general population but there is not a clear consensus about treatment, considering that this could create a greater level of dependency in the patient (29).
- 7.3.9 Multi-professional teamwork can contribute to a remarkably good prognosis for the ventilator-dependent tetraplegic patient. Age at injury is prognostically significant. The life expectancy for the individual improves after the first two years, resulting in a life expectancy of 50% predicted for each age group (30).
- 7.3.10 Treatment withdrawal may be discussed at times by a ventilator-dependent tetraplegic person, particularly early after acute injury and again much later in the case of those already tetraplegic for a number of years. Apart from general sources cited under the withdrawal and withholding treatment guidelines, issues within the context of high tetraplegic are reviewed elsewhere (31).
- 7.4 The size of the patient group receiving long term home ventilation
- 7.4.1 A census of patients receiving domiciliary ventilation was performed in November 1999. Responses were received from 26 Units, including 7 dealing with patients following spinal injury and 2 with paediatrics. 2321 patients were identified, of whom 30 were awaiting transplantation. A more detailed study is under way currently as part of a European Union Concerted Action programme.

8.0 NIV and weaning from mechanical ventilation

The majority of patients who require invasive mechanical ventilatory support either wean successfully or die during their Critical Care admission. However, a small, but significant, sub-group require either a prolonged Critical Care stay in order to wean, or may become ventilator-dependent. This has important health economic implications. A North American study, now over a decade old, found that this group of patients consumed 37% of the total Critical Care resources in 12 large hospitals (32). Since this report, a number of new approaches have been made to the problem, including:

- The identification of patients with advanced chronic respiratory failure in the outpatient setting and discussion of their preferences for ventilatory support during future exacerbations. Following informed discussion of likely outcomes, many patients made advanced directions against invasive ventilatory support in one North American study (33).
- Attempts to avoid intubation using NIV
- Clinical trials showing improved speed of weaning with sedation withdrawal and weaning protocols
- Clinical trials of weaning by extubation onto NIV
- Early discharge of ventilator-dependent patients to weaning/intermediate care areas.

- 8.1 Incidence of prolonged ventilation
- 8.1.1 Using the definition adopted by the North American Health Care Financing Administration (the need for mechanical ventilatory support for greater than 6 hours per day for 21 days and over), a survey conducted in Massachusetts in 1986 found 147 patients requiring prolonged ventilation. Based on this data, the authors estimated that 6,800 patients in North America were ventilator-dependent at the time of the study (34).
- 8.1.2 In 1990 the American Association for Respiratory Care and the Gallup organisation conducted a cross-sectional telephone survey of ventilator dependency in North America based on random sampling. They used a definition of 6 or more hours per day for 30 or greater days. They estimated that 11,000 patients in North America were ventilator-dependent at that time (35).
- 8.1.3 Further estimates come from a repeated study performed in Massachusetts in 1995, which found 145 dependent patients with an extrapolation to 7,250 in North America (36).
- 8.1.4 These surveys included all patients requiring ventilation and not only those receiving mechanical ventilation in critical care. In the second Massachusetts survey, 46% of the patients were receiving mechanical ventilation (MV) in a post-acute care facility. There is no doubt that some of the drive to establish these units has been financial. The cost of care is significantly reduced, mostly as a result of lower nursing numbers. However, in the ICU there is some evidence that duration of MV is related to nurse:patient ratios, a significant increase in the duration of MV being detectable when nursing numbers are reduced (37).
- 8.1.5 No comparable UK data on hospital inpatient ventilator dependency existed until recently. Extrapolation from the North American work on a population basis suggests that approximately 2400 patients in the UK are likely to be chronically ventilator-dependent. A survey carried out in 1998 in fact identified 2400 patients receiving ventilatory support in the domiciliary setting, although this is likely to be an underestimate.
- 8.1.6 A number of studies have estimated the incidence of prolonged MV in the ITU setting. Ely and collaborators studied 300 consecutive ventilated patients in a study of weaning protocols. In 15% there was weaning delay (38). Brochard and co-workers (39) conducted a study comparing three different modes of weaning (T-piece, SIMV, pressure support, PS) on 456 patients. 5.5% were ventilator dependent at 21 days. Other studies report an incidence of a prolonged ventilation of all ICU patients in the order of 5-13% (summarised in 40).
- 8.2 Influences upon the duration of mechanical ventilation
- 8.2.1 The duration of mechanical ventilation is influenced by several factors including diagnosis, age of the patient, severity of initial illness and psychosocial factors. Seneff and co-workers (41) reported on outcomes in 5,915 ventilated patients in 42 US ITUs from 1988 to 1990. Variables associated with prolonged ventilation included reason for ITU admission, day one acute physiology score, prior patient location and duration of hospital length of stay, activity limits due to respiratory disease and severity of gas exchange problems. Patients with chronic respiratory disease were at higher risk of needing prolonged mechanical ventilation.
- 8.2.2 The hospital mortality of patients receiving prolonged, conventional MV is high and summarised in Table 1. These studies indicate that hospital mortality is in the region of 50%.in conventionally intubated patients receiving prolonged MV.

8.3 Improving weaning success rates

- 8.3.1 There is some evidence that both the number of patients needing prolonged MV and their outcomes can be improved by specific approaches to weaning and the use of weaning protocols.
- 8.3.2 Both T-piece trial and PSV reduction are likely to be superior to SIMV for weaning. A systematic review (42) compared these three modalities and found that in difficult-to-wean patients, SIMV produced significantly greater numbers of patients needing prolonged (> 21 days) MV compared to the other methods used.
- 8.3.3 There is evidence suggesting that duration of ventilation is reduced in patients cared for by health care workers following set weaning and extubation protocols (38). These trials were all conducted in North America where staffing levels, case mix and the role of critical care physicians differ from those of the UK. It is likely that weaning protocols would be effective in the UK but this remains to be established.
- 8.3.4 Only awake patients can be weaned. Sedative drugs accumulate in the critically ill and can cause prolonged coma. A better outcome in patients who underwent daily trials of sedation cessation has been recently demonstrated in a randomised controlled trial (43).
- 8.3.5 Patients with COPD who fail an initial T-piece weaning trial may benefit from early extubation on to NIV. Girault and co-workers reported a reduced duration of endotracheal MV in groups of difficult-to-wean patients with acute or chronic respiratory failure extubated onto NIV (44). However, total duration of ventilatory support was increased and length of hospital stay and 3-month survival were similar in NIV and conventionally managed groups. Nava's group (45) performed a similar study, comparing weaning via NIV to PS weaning in 50 patients intubated for exacerbations of COPD. Mean duration of ventilation was significantly less in the NIV group, as were the number of patients successfully weaned at day 60. Sixty-day survival was also better in the NIV group.

Newcastle General Hospital Intensive Care Weaning Service

This is a multidisciplinary service involving two Intensivists, one with a background in Respiratory Medicine and the other in Anaesthesia, a Senior Nurse Specialist and Senior Physiotherapists. Team members assess patients with weaning difficulties at the referral unit. Following local assessment a weaning strategy is devised. This may consist of continued attempts at weaning at the referral unit, supported by the Weaning Team, or transfer of the patient to Newcastle for further management including short or long term transition to NIV. Approximately 30 referrals are made each year from hospitals within an area corresponding to the old Northern Region. More than 90% of referrals successfully wean from ventilation and most return to an independent life at home.

For more information contact: Dr Simon Baudouin, Senior Lecturer in Intensive Care, University Department of Anaesthesia, Leazes Wing, Royal Victoria Infirmary, Newcastle upon Tyne, NE1 4LP; Tel: 0191 2325131 ext. 24058; Email:s.v.baudouin@ncl.ac.uk; or Dr Robert Bullock, Consultant in Anaesthesia and Intensive Care, Department of Anaesthesia, Newcastle General Hospital, Westgate Road, Newcastle upon Tyne, NE4 6BE; Tel: 0191 2738811 ext. 22535; email: robert.bullock@trvi.nuth.northy.nhs.uk.

Lane Fox Respiratory Unit Weaning Programme, St Thomas' Hospital

This 16-bed unit provides a comprehensive programme of assessment in chronic respiratory failure. It supports more than 400 home ventilation individuals (including 24 hour technical help) for those mostly living in the South of England. A multidisciplinary service for weaning failure has been developed and over 200 transfers from Critical Care Units have been taken in the past 4 years. The programme has been audited with a weaning success in 50-70% depending upon aetiology. One and two year survival for those weaned from invasive ventilation is 55-80% with post op and neuromuscular disease survival being better than COPD. Contacts with long stay facilities have been developed for those who are unable to return home whilst training programmes for carers and liaison with health authorities and social services form part of the comprehensive discharge package. An outreach programme to provide advice and support to referring hospitals is currently under development.

For more information contact: Dr Craig Davidson, Head of Service or Dr Adrian Williams at the Lane Fox Unit, St Thomas' Hospital, London, SE1 7EH; Tel: 0207 927 9292 ext. 6866; Fax: 0207 922 8281, email: craig.davidson@gstt.sthames.nhs.uk

Progressive Care Programme, Papworth Hospital NHS Trust

This specialist weaning service has received over 300 referrals from all over the UK in the past six years. The patients are transferred from critical care areas because of weaning failure, and through a multi-disciplinary approach and the use of NIV more than 90% have survived and been discharged from hospital; more than 80% have returned to an independent life in the community.

For more information contact: Dr. J. Shneerson FRCP, Progressive Care Programme, Respiratory Support and Sleep Centre, Papworth Hospital NHS Trust, Papworth Everard, Cambridge CB3 8RE Tel: 01480 830541; Fax: 01480 830620; Elaine.Simpson@papworth-tr.anglox.nhs.uk

8.4 Cost effectiveness of prolonged MV and weaning programmes

- 8.4.1 Long-term ventilated patients are major resource users within Critical Care. A survey in North America has established that whilst only 6% of ITU admissions were ventilated for 7 or more days, they consumed 37% of resources during their stay (46). At least 60% of Intensive Care Unit costs are personnel-related and considerable savings could be made by caring for patients requiring prolonged ventilation in a less staff-intensive environment.
- 8.4.2 There is a large body of literature on the economics of prolonged ventilation, but almost all publications originate in North America. When extrapolating information to the United Kingdom, trans-Atlantic differences in practice should therefore be considered. Secondly, much of the information is now at least one decade out of date. Nevertheless, the costs of caring for patients requiring prolonged MV in North America appear to be substantial. In 1990 it was estimated that the total annual cost of ventilating patients with tracheostomies in North America was \$3 billion (47). A second survey from New York State in 1993 estimated, from diagnostic codes, that \$650 million was spent on the care of long-term ventilated patients (48). Further studies, all from North America, have demonstrated 20% to 60% reductions in the daily costs of chronically ventilated patients when treated in a non-ICU, compared to an ICU acute hospital setting (reviewed in 49). Extrapolation to UK models of care is difficult. North American ITUs are often staffed at a nurse/patient ratio of 1:2 but have a greater number of para-medical support staff, including Respiratory Therapists. Staffing levels for weaning units are also variable, but nurse/patient ratios of between 1:3 and 1:6 are common.

- 8.4.3 It is reasonable to assume that a 50% cost saving per patient day could be made in the UK by caring for chronically ventilated patients in a Level 2 setting rather than a Level 3 setting. Some estimate can be made from the North of England survey on weaning (Section 10.1) of the economics of long-term ventilation in the UK. Over a one year period, patients located in Level 3 facilities but only receiving respiratory support via tracheostomy, occupied approximately 1,000 bed days in the Region (50). Assuming a basic Level 3 cost of £800 per day and a Level 2 cost of £400 per day, a saving of approximately £400,000/year could be made in this Region by caring for such patients in a Level 2 setting. Extrapolation to England suggests cost savings in excess of £5 million/annum could be made.

NHS / Private Healthcare Partnership: Specialist Weaning Unit

A multidisciplinary team is currently developing a specialist weaning unit within the Critical Care Unit of the London Clinic. This innovative venture plans to admit patients from local NHS critical care units who have difficulty in weaning from mechanical ventilation. It will focus on those patients who have the potential to wean but require a more focused and rehabilitative framework of care in order to do so. Secondary aims of the initiative are to carry out prospective audit to assess the effect of specialist weaning units, to increase Critical Care resources within the NHS and to assess the potential of public:private partnership within critical care.

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9.0 Estimates of weaning requirements in UK Critical Care Units

9.1 The North East of England & Cumbria Survey

The North East & Cumbria Critical Care Network has surveyed the incidence of weaning problems over a six month period. Out of a total of approximately 3,000 admissions, 2.6% of patients were still requiring MV at 21 days or over and were sufficiently stable to be considered for weaning. This provides a conservative estimate of the number of patients who may benefit from weaning using NIV (approximately 160 patients/year in this Network).

Summary of outcome studies of patients receiving prolonged MV in the Intensive Care setting

Study	Year	Number	Duration of MV	Mortality
Seneff ¹⁰	1988-90	1195	>7 days	54%
Kurek ¹⁶	1993	6365	All underwent tracheotomy	51%
Gracey ¹⁷	1986-88	104	29+ days	43%
Spicher ¹⁸	1981-86	245	10 or greater days	61%

9.2 The NHS Modernisation Agency's weaning survey (Appendix 1)

Only hospitals with adult Level 3 facilities within England were surveyed. A total of 242 questionnaires were dispatched and 158 returned (response rate 65%), identifying 1075 patients occupying Level 2 and 3 beds.

9.2.1 Nature of the hospitals and ICUs

Details of hospital type and number are shown in Figure 1 and Table 1. The total numbers of Level 2 and Level 3 beds in 158 hospitals are shown in Table 2. The average number of Critical Care consultants per unit was 5 (range 1-10). The majority of units within the 158 hospitals were mixed in terms of their patient population.

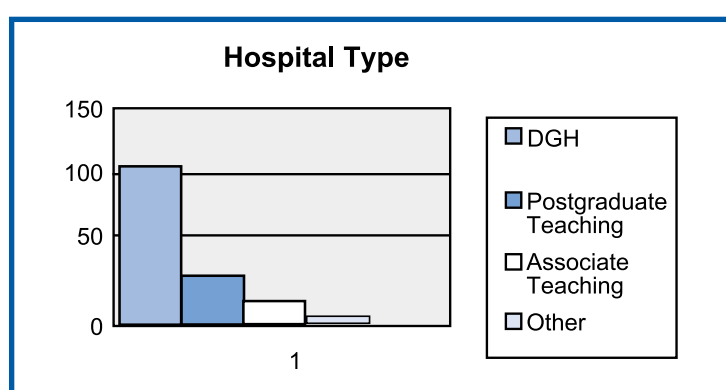
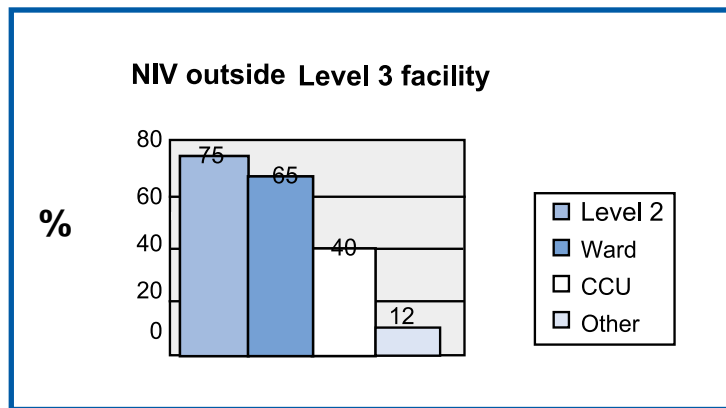


Table 1: Number of Hospitals by type

Hospital Type	Number
District General	114
Postgraduate Teaching	30
Associate Teaching	13
Other	1

Table 2: Level 2 & 3 Beds

Level of Bed	Number
Level 2 Beds within the individual units	400
Level 3 Beds within the individual units	1013
Level 2 & 3 Beds within the hospital	1784



9.2.2 Non invasive ventilation (NIV): Numbers and type of patients

NIV took place in various settings (Figure 2). The “other” areas which conducted NIV outside Critical Care included A&E, the community, theatre recovery areas, medical assessment units, paediatric HDUs and sleep laboratories. The accuracy of answers to the question “How many patients were treated with NIV in the past month?” is difficult to quantify. Many of the units did not have data and numbers were often estimated. This was particularly true for those areas outside the Critical Care Unit where there appeared to be little or no data collection. The total estimated number of patients treated with NIV in a month was 736.

The most common reasons for using NIV were: Type II respiratory failure, exacerbation of COPD and weaning from IPPV.

9.2.3 Approaches to weaning from mechanical ventilation

Thirty-four (22%) hospitals referred 73 patients to a specialist unit for weaning within a 12 month period. Weaning patients from mechanical ventilation was clinician-led in the majority of units (Table 3). Very few units used protocols/algorithms or specialist weaning teams to guide the weaning process. “Other” methods included a mixture of protocols and clinician preferences.

Table 3: Weaning strategies

Type	Number
Protocol / Algorithm led	33
Clinician led	152
Specialist weaning team	2
Other	8

9.2.4 Weaning delay or failure

A total of 161 patients in 59% of the hospitals answering the survey fulfilled the criteria for weaning delay or failure (Table 4). The average age of such patients was 62 (range 19 to 88) years. A majority had medical problems such as pneumonia, COPD, ARDS, MI and pancreatitis. 93% of patients had co-morbidity, and many more than one. The commonest co-morbidities were cardiac disease and COPD (Table 5). Severity of illness (by APACHE II) scores on admission were available for 92 out of the 161 (57%) patients and ranged from 5-46 (mean 20). There were 16 (10%) Critical Care re-admissions in this patient group during a single in-patient episode. The most common reason for weaning delay or failure was lung disease (Table 6). The average number of reasons for delayed or failed weaning per patient was 3 (range 1 to 5).

Table 4: Weaning Delay / Failure

Patients	Number
Weaning Delay	85 (8%)
Weaning Failure	76 (7%)

Table 5: Co-morbidity

Co-morbidity	Incidence
Cardiac Disease*	43
COPD	34
Renal Failure	14
Hypertension	12
Diabetes (IDDM)	8
Obesity	6
Peripheral Vascular Disease	6
Restrictive Lung Disease	5
Depression	5
Asthma	3
Quadriplegia	2
Other (*Cardiac Disease includes IHD, LVF, AF)	23

Table 6: Reasons for weaning delay / failure

Reasons	Incidence
Lung disease	91
Cardiac Impairment	47
Neuromuscular / neurological disease	43
Chest wall deformity	7
Critical care polyneuropathy / myopathy	39
Excessive secretions	46
Psychological	34
Other	23

9.2.5 Referral to specialist weaning units

Patient referral and estimated length of stay are shown in Tables 7 and 8. The number of patients who were referred to a specialist weaning unit appears to be less than 10%. However, many respondents did not answer the question, which may have been inappropriately structured. Some units commented that they did not refer their patients, as there was nowhere to refer them to.

Table 7: Patient referral

	Number
Patients referred to specialist unit	14
Patients suitable for transfer to specialist unit on day of survey	62
Patients suitable for transfer in future	38

Table 8: Estimated length of stay

Number of weeks	Patient Number
>3 weeks	30 (19%)
1-3 weeks	73 (45%)
< 1 week	59 (37%)

9.2.6 Limitations of the survey

- Some forms were incomplete.
- The suggestion that 1075 beds were occupied at the time of the survey implies there were some 709 Level 2/3 beds not used within the 158 hospitals. However, the figure of 1075 is unlikely to be accurate as survey forms were frequently completed centrally and not passed to other areas within the surveyed hospitals with Level 2/3 beds but outside the administrative structure of the unit to which the survey was addressed.
- There was confusion concerning the definitions of Level 2 and 3 dependency.
- Some units did not agree with the definitions of weaning delay or weaning failure employed in the survey.
- The survey did not distinguish between male or female patients.
- No specific day was identified upon which the form was to be completed.

10.0 Management protocols concerning the use of NIV

A review of publications giving current guidelines and best practice for the use of NIV in weaning and long term ventilation is given in Appendix 2.

11.0 Acute respiratory failure and the use of NIV: Recommendations (Appendix 3)

We recommend that an NIV service be established in each acute Trust for the management of patients with acute respiratory failure on the basis that:

- 11.1 Non-invasive ventilation (NIV) reduces the need for intubation, duration of ventilation and mortality in patients with acute exacerbation of COPD. This may lead to a reduction in ICU admissions.
- 11.2 Selected patients with non COPD acute respiratory failure (ARF), e.g. due to acute pneumonia, immunosuppression, post surgery, may benefit from NIV.
- 11.3 NIV reduces complication rates partly due to a reduction in infectious consequences of intubation, e.g. nosocomial pneumonia.
- 11.4 NIV provides patients and their carers with access to an alternative form of ventilatory support that may be more suited to their individual needs.
- 11.5 Level 2 facilities provide a useful focus for training and delivering NIV.
- 11.6 The Committee recommends that such a service should be:
 - 11.6.1 Available continuously
 - 11.6.2 Led by a suitably qualified team of consultant clinical staff, working to defined and accepted clinical protocols
 - 11.6.3 Integrated with, and complementary to, the existing Level 2 and Level 3 facilities of the Trust
 - 11.6.4 Supported by nursing and AHP staff appropriate to the dependency of the patients
 - 11.6.5 Equipped to standards specified by the British Thoracic Society
 - 11.6.6 A training facility for ALL junior medical, nursing and AHP staff involved in the care of the acutely ill
 - 11.6.7 Equipped with data collection and audit facilities.

12.0 Delayed weaning: Recommendations

We recommend that a specialist NIV service to which patients who suffer delayed weaning can be referred should be established in a small number of NHS Trusts where there is appropriate experience on the basis that:

- 12.1 The service is of likely benefit to patients with delayed weaning
- 12.2 The service is cost effective

The Committee recommends that such a service should be:

- 12.3 Available according to patient need
- 12.4 Integrated administratively within the Critical Care Network system where possible.
- 12.5 Available as an outreach assessment and distant management service to Trusts within the defined catchment area
- 12.6 Led, staffed, organised and managed clinically according to standard protocols (which may need to be developed and validated)
- 12.7 Equipped with data collection and audit facilities.

13.0 Failed weaning, long term ventilatory support and NIV: Recommendations

We recommend that a UK-wide service for the provision of long term invasive and non invasive ventilatory support, and for patients who have failed weaning, should be established. This should be provided by specialist units experienced in the provision of long term and domiciliary ventilatory support. This is justified by:

- 13.1 The survival advantage seen in specified patient groups (e.g. chest and spinal deformity, neuromuscular disease) undergoing NIV
- 13.2 A possible survival advantage and reduction in the need for hospitalisation in patients with stable ventilatory failure secondary to chronic lung disease
- 13.3 The desirability of transferring patients who have failed weaning into the community.

The Committee recommends that such a service should be:

- 13.4 Available according to patient need
- 13.5 Integrated administratively within the Critical Care Network system where possible
- 13.6 Available as an outreach assessment and distant management service to Trusts within the defined catchment area
- 13.7 Led, staffed, organised and managed clinically according to standard protocols (which may need to be developed and validated)
- 13.8 Equipped with data collection and audit facilities.

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Appendix 1: Survey form used in NHS Modernisation Agency national survey (Section 10)

NATIONAL SURVEY OF PATIENTS WHO ARE DIFFICULT TO WEAN

Hospital Name

Hospital Address

Post Code

About your Unit / Hospital

Dr in Charge of Unit

Senior Nurse

Email

Email

Type of Hospital
(Please tick)

Type of Unit

Associate Teaching
District General
Postgraduate Teaching Hospital
Other

Medical
Surgical
Mixed
Neuromedical
Neurosurgical
Cardiothoracic
Renal
Liver
Burns
Other

Please state number of intensive care consultants:

Please state number of:

Level 2 beds within your unit	
Level 3 beds within your unit	
Level 2 & 3 beds within your hospital	

01. Do you have any ICU step down facilities available to you? (Please tick)

YES NO

01.1 If “yes” indicate type: (Please tick)

Medical
(If sub types please state)

Surgical
(If sub types please state)

01.2 Do any of these step down facilities provide Invasive ventilatory support?

YES NO

02. Do you undertake non-invasive ventilatory support (eg. CPAP, NIV) outside ITU? (Please tick)

YES NO

02.1 If “YES” where? (Please tick all that apply)

CCU

HDU

Ward

Other (Please state)

02.2 Please indicate type of ventilatory support (invasive and non-invasive) used within each area:

	IPPV (via tracheostomy/ETT)	NIV	Non-invasive CPAP	Other (Please state)
CCU				
HDU				
Ward				
Other (Please state)				

02.3 How many patients have been treated with NIV in the past month:

Number.....

02.4 Please indicate the reason for NIV treatment:

02.5 Please indicate the nurse-patient ratio in those areas that undertake non-invasive ventilatory support:

	Nurse-Patient Ratio
CCU	
HDU	
Ward	
Other (Please state)	

03. How many patients from your unit with weaning delay or delay have been referred to a specialist unit for weaning in the last 12 months?

Number.....

04. What strategy do you employ to direct the weaning process? (Please tick)

Protocol / Algorithm led	
Clinician led (clinician preference)	
Specialist Weaning Team led	
Other (please state)	

SNAPSHOT DATA: Information about what is happening on your unit TODAY

05. How many patients were on your unit at 10.00 hrs today?

Number.....

06. How many patients fulfilled the following criteria:

Weaning Delay: >14 days in ICU where respiratory dependency is now the primary problem and the patient requires invasive ventilatory support for >6 hours per day.

Weaning Failure: >21 days in ICU where respiratory dependency is now the primary problem and the patient requires invasive ventilatory support for >6 hours per day.

NB: If you have an area outside ICU that provides invasive ventilatory support please ask them to provide the following information.

06.a At 10.00 hours today how many patients were on this unit / ward?

Number.....

06.b Did any of the patients fulfill the criteria for Weaning Delay or Weaning Failure?

YES Number..... NO

If “YES” please fill in the following form for each patient identified.

06.2 Please fill in the following details on all those patients who fulfilled the weaning delay / failure criteria:

(Use **one** form for **each** patient identified)

Age of patient	
Weaning Delay OR Weaning Failure	
Primary Diagnosis	
APACHE II score on admission APACHE II score today	
Date of first admission to ICU during this hospital admission	
Has this patient been readmitted to the ICU during this episode of hospital stay?	
Tracheostomy?	
Date of procedure:	

State nature of Co-morbidities:

Active

Inactive

Reasons for weaning Delay or weaning Failure (Please indicate those that apply in order of importance: 1 = most important etc):

Lung disease	
Cardiac impairment	
Neuromuscular disease	
Chest wall deformity	

Critical care polyneuropathy / myopathy	
Excessive secretions	
Psychological (eg. Anxiety, fear, agitation etc)	
Neurological deficit	
Other (please specify)	

Has this patient been referred to a Specialist Weaning Unit?

YES NO Date of referral: / /

Would this patient be suitable for transfer to a Specialist Weaning Unit (a Unit able to take fully ventilator dependant patients with single organ (lung) failure or additional organ failure that is stable)?

YES NO

How much longer do you anticipate that this patient will need to remain on your ICU?

Less than one week 1 to 3 weeks > 3 weeks

Do you think that transfer to a Specialist Weaning Unit might be an option in the future?

YES NO

If "yes" please estimate approximate date / /

Appendix 2: Examples of guidelines, best practice care, and consensus conferences on weaning, NIV, and discontinuation of ventilation

I. Acute NIV and level 3 bed use

- i. Non-invasive ventilation: State of the Art Mehta S, Hill NS Am J Respir Crit Care 2001; 163: 540-577: Summarises most up to date outcome information on the use of NIV in acute respiratory failure, for weaning patients and application in long term ventilator dependent patients. Useful overview and source of original references.
- ii. International Consensus Conference in Intensive Care Medicine: Non-invasive positive pressure ventilation in acute respiratory failure. Evans T.W. Int Care Med 2001; 27: 166-178: Examines rationale, goals, and modes of NIV in acute respiratory failure, weaning, 'do not resuscitate' and post surgical patients with recommendations for further research.
- iii. Non-invasive ventilation in acute respiratory failure: British Thoracic Society 2000. Currently in draft form on British Thoracic Society website. Publication due 2001. Summary of best practice guidelines for implementation of NIV in hospital and selection of patients for home NIV.
- iv. Non-invasive ventilation for acute exacerbations of COPD: a new standard of care. Brochard L. Thorax 2000; 55: 817-818. Editorial authoritatively outlining evidence-based plan for the step-wise management of acute respiratory failure in COPD patients on the ICU and ward.
- v. Respiratory Intensive Care in Europe: lessons for the UK. Elliott MW. Baudouin SV. Thorax 1998; 53: 725-726. Editorial on the rationale for the expansion of high dependency unit care in the UK to provide step up and step down beds and act as focus for development of NIV.

II Weaning protocols

- i. Intensive Care Society National guidelines (UK) 2000: Useful summary but: presupposes weaning is all or nothing; inadequate emphasis on the need for muscle rest during slow weaning in combating fatigue; inadequate emphasis on the need for psychological support care for slow weaners; no mention of concurrent rehabilitation needs for slow or non-weaners.
- ii. Is there a preferred technique for weaning the difficult to wean patient? A systematic review of the literature. Butler R et al. Crit Care Med 1999; 27: 2331-2336: Reviews 667 studies, 4 fulfilling selection criteria. One conclusion is that SIMV may result in longer weaning times than T-Piecing ore pressure support. A second conclusion is that how the techniques is applied is as important as the actual technique. Thirdly use of a protocol or guidelines in itself leads to a decrease in weaning time.

III. Long term ventilation

- i. Consensus Conference. Clinical indications for noninvasive positive pressure ventilation in chronic respiratory failure due to restrictive lung disease, COPD and nocturnal hypoventilation - a Consensus conference report. Chest 1999; 116: 521-534: Results form expert based opinion on the indications for long term NIV in adults with restrictive disorders and COPD. Not all conclusions evidence-based, but clear 'best bet' guidelines given.

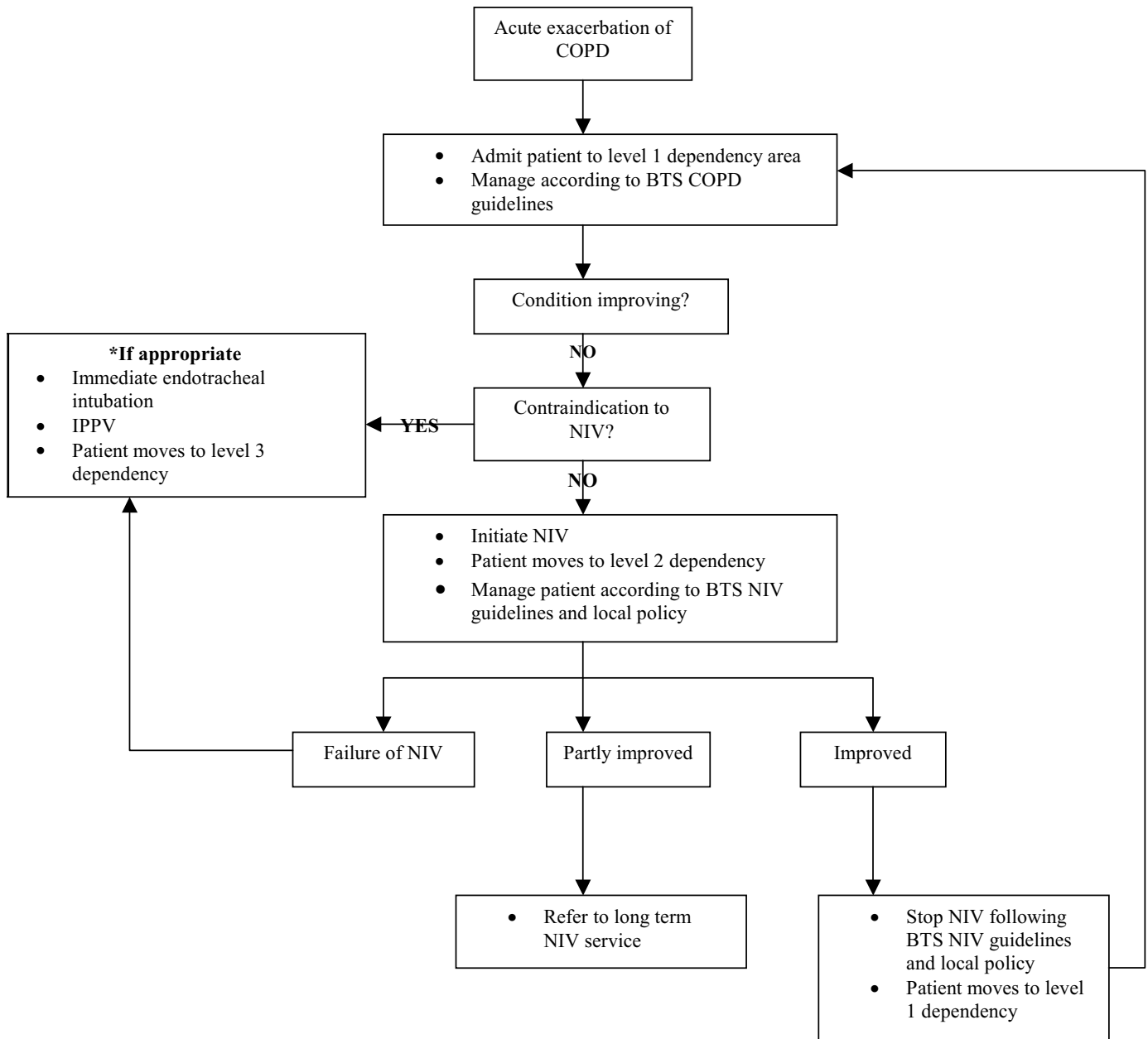
- ii. Mechanical ventilation beyond the Intensive Care Unit. *Chest* 1998;113: 289S-344S. Report of a Consensus Conference of the American College of Chest Physicians: Provides 60 recommendations for best adult and paediatric practice, in addition to substantial background detail, most of which is relevant to the UK even though written from a US standpoint.
- iii. Core guidelines for the discharging home of the child on long term assisted ventilation in the UK. Jardine E, Wallis C. *Thorax* 1998;53: 762-767. (Based on consensus from expert working group): States that 'in most cases a period of evaluation at a tertiary hospital will be necessary to complete a comprehensive assessment of needs'; covers definitions, criteria and objectives, demographics, model of care delivery, case management, needs assessment, the discharge process, home care, training and education, follow-up and emergency care; confirms the acceptability of non-professional care givers as part of the home care package, providing they have been trained and assessed as competent in providing care; recommends that the home ventilator care package is co-ordinated by a trained nurse.
- iv. A specification for the provision of Paediatric Long Term ventilation for the area covered by the NHS Executive North West Region (UK). Working group recommendations 2000. Patient group, though specifically paediatric through to adolescence, has themes in common to adults; the model described relates to existing Lead centres for paediatric Intensive care in the NW region. Nationally there is no planned service distribution for the difficult to wean or non-weaning patient. Recommends 'consideration to be given to establishing pre-agreed criteria and principles on which to base funding with these authorities in order to speed the process for individual children'. However, the region itself ought to play a lead role in such an initiative as most funding needed originates from health authorities and for expensive cases it might be reasonable to devolve funding upwards. Acknowledges that carers for ventilator dependent patients need not be qualified as nurses, although they must be trained in their patient's specific care.
- v. Care of the child with a chronic tracheostomy. Official statement of the American Thoracic Society. *Am J Respir Crit Care Med* 2000; 161: 297-308: Useful summary on the practicalities, competency training and best practice for long term tracheostomy ventilation with crossover relevance to adult home tracheostomy care.

IV. Withdrawal of and withholding treatment

- i. Withholding and withdrawing life-prolonging treatment. Guidance for decision-making. British Medical Association 1999. Withholding life-sustaining treatment in intensive care. Bonner S, Pace N. *British Journal of Intensive Care* July/August 2000; 123: 123-129: Advance Statements about medical treatment.

Appendix 3: Illustrative Care Pathway: Acute use of NIV

Figure: Illustrative Care Pathway: Acute use of NIV



*The decision to use IPPV should have been discussed with the patient and family prior to further deterioration.

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