Rehabilitation after critical illness

Full guideline

Draft for consultation, November 2008

This guideline was developed following the NICE short clinical guideline process. This document includes all the recommendations, details of how they were developed and summaries of the evidence they were based on.

Contents

Disclaimer

NICE clinical guidelines are recommendations about the treatment and care of people with specific diseases and conditions in the NHS in England and Wales.

This guidance represents the view of the Institute, which was arrived at after careful consideration of the evidence available. Healthcare professionals are expected to take it fully into account when exercising their clinical judgement. However, the guidance does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or guardian or

carer, and informed by the summary of product characteristics of any drugs they are considering.

Implementation of this guidance is the responsibility of local commissioners and/or providers. Commissioners and providers are reminded that it is their responsibility to implement the guidance, in their local context, in light of their duties to avoid unlawful discrimination and to have regard to promoting equality of opportunity. Nothing in this guidance should be interpreted in a way which would be inconsistent with compliance with those duties.

Foreword

Approximately 70,000 people spend time in intensive care units in England and Wales each year; the majority survive to be discharged home. The general perception among patients, families and most healthcare professionals is that these people undergo a rapid convalescence and recover to their previous life, in terms of both quantity and quality.

Until relatively recently, there was little systematic understanding of what really happens to all of these people. In the United Kingdom, a handful of hospitals established specialist follow-up clinics, staffed initially by doctors and nurses who also worked in the intensive care unit, and who thus understood the context of the patient's clinical story; much of this work was on a very precarious financial footing. Recently it has been established that up to 30% of intensive care units run such clinics.

Academic study based on these services, a field in which the United Kingdom has been a leader, has demonstrated that a significant proportion of patients surviving critical illness have important continuing problems. For these individuals, discharge from critical care is the start of an uncertain journey to recovery punctuated by, amongst other things, weakness, loss of energy and physical difficulties, anxiety, depression, post traumatic stress phenomena and for some a loss of mental faculty (termed cognitive function). Family members become informal care-givers, and this itself can exert a secondary toll of ill-health; family relationships can become altered and financial security imperilled.

Against this background, optimisation of recovery as a therapeutic objective, rather than mere survival, has developed increasing prominence. Identified as an important area during the creation of the Care of the Acutely Ill Patient guideline, the Department of Health charged NICE 'To prepare a clinical guideline on the rehabilitation of adults after a period of critical illness requiring a stay on ITU.', and this series of documents represents the result of the process.

To the non-specialist, the terminology around critical illness can be confusing. “Critical care” is now used as a term that encompasses “intensive care” or “intensive therapy”; units providing such care being referred to as intensive care (ICU) or intensive therapy (ITU) *units* respectively (and synonymously), together with what used to be called “high dependency “ care provided in “HDU”s.

Further, although this may seem a somewhat incongruous way of dealing with things, we have chosen to divide the potential consequences of critical illness into “physical” and “non-physical” domains, the latter to encompass all the non physical symptoms one might envisage, such as anxiety, depression, post-traumatic stress disorder, and cognitive dysfunction. This was done for simplicity and to avoid confusing the reader with subtle but confusing professional niceties.

The population intended to be covered by this guideline is that of general adult critical care for whom no alternative rehabilitation pathway currently exists. Patients served by multi dimensional neuroscience units, cardiac services and burns units- amongst others- already have the provision of rehabilitation in many parts of the country, and this guideline is not intended for such groups. Also excluded are the large numbers of patients who have brief stays in critical care units for immediate post-operative care after major elective surgery; however patients whose post-operative course deviates from the anticipated course would be covered.

There is no particular requirement for a specified period of ventilatory support as an entry criterion for this pathway. Comments from the initial stakeholder meeting drew attention to the numbers of trauma patients, many of whom receive ventilatory support for brief periods of time, yet who have the potential to benefit greatly.

The Guideline Development Group (GDG) identified to engage with this task consisted of a blend of intensive care and rehabilitation medicine consultants and nurses, rehabilitation professionals and crucially ex-patients and carer

representatives, all with substantial records of clinical service, research, support or advocacy in relevant fields.

What became rapidly clear as the GDG and the NICE technical team set about reviewing the evidence was that the substantial body of evidence generated by follow up studies was dominated by observational work, and the number of good quality randomised intervention trials was extremely small, and this is reflected in the recommendations and evidence reviews. The GRADE schema of generating evidence based guidelines was adopted for the recommendations concerning interventions, and this process is reflected in the evidence to recommendations sections. This method allows for a dynamic review of studies against a range of assessments, rather than a somewhat static set of criteria.

Thus the wealth of experience, clinical and personal, brought to the process by the membership of the GDG was of primary importance. Consistent with the NICE Guideline Development Manual, a number of recommendations were produced based on GDG expert consensus.

The GDG felt very strongly that, even where relevant services existed, care was often delivered in a piecemeal manner and that central to improving this would be the embedding of specific communication along the patient's recovery pathway (echoing the guidance for the Acutely Ill Patient), including the interface between secondary and community based care, and that the elements of the pathway needed to be coordinated by suitably trained and experienced healthcare professionals. Such individuals could come from a variety of professional backgrounds or services depending on local service arrangements, but should be a constant and available lynchpin on which patients and families/carers may depend.

Also recognised by the GDG was the strain suffered by many families, and frequently the commitment to helping the recovering patient. There is a tension between the provision of information to assist families in coping, and the recognition that many patients may not wish specific information to be shared and patient autonomy must be respected.

Many families suffer financial strain as well as strain on their health and emotional resources. It was recognised that information around social services and benefits is often difficult to obtain and understand by those who need it, and decisions made around this area occasionally seem arbitrary; however, although there is clear room for improvement, it was difficult to see how this could be incorporated into the Guideline beyond generalities, given how often such guidance would need to be changed.

Several factors limit the economic modelling relevant to this Guidance. Firstly, the NICE economic model analyses at the patient level only and compares incremental costs of different interventions, thus broader societal costs are not included. Secondly, the lack of suitable data from randomised trials precluded detailed study. It is clearly vital that future interventional studies that may identify useful interventions are designed in a manner that allows them to survive scrutiny on a health economic basis.

For many patients the recovery after critical illness is relatively straightforward and it is important not to lose sight of this. Virtually all of the observational data come from modestly-sized studies of proportions of patients returning to follow up clinics or completing surveys of one form or another. All of these studies are inevitably vulnerable to enrolment bias, which may confound results; thus there is genuine uncertainty over numbers. What is clear is that tens of thousand of patients leave critical care to go home each year, and even with generous confidence intervals around prevalence estimates of morbidity, this represents a substantial problem. Given the individual impact on patients and “ripple” effects on families and society in general, poor quality rehabilitation and impaired recovery from severe illness should be regarded as a major public health issue.

The GDG has made a series of specific research recommendations detailed later in the document. Additionally, of particular strategic importance is the lack of detailed understanding of the pathophysiology of, and recovery from, the muscular wasting which is a feature of critical illness and this area needs to be addressed. Alongside this, a better understanding of the impact of critical illness on the brain, and its relationship to sedation, neuro-

inflammation, delirium and future cognitive impairment is a priority. There is scope here for interventional trials in the near future. A thorough understanding of the social economic consequences of critical illness at an individual and society level is also required to inform broader policy.

From my perspective as GDG Chair the development process has been a challenge. It is one thing to know that a problem exists, and quite another to translate knowledge of a problem into an evidence based management guideline, the implementation of which can be delivered in an NHS context ultimately for the benefit of patients. The GDG and the technical team have worked extremely hard picking their way through firstly a difficult and somewhat patchy evidence base, and secondly the constraints of the NICE process; I am grateful for their commitment and effort. Our ambition is that this Guideline will lead to substantial benefits for recovering patients and their families. We would hope that when this Guideline is reviewed the evidence base for specific interventions and service delivery models is more substantial.

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Patient-centred care

This guideline offers best practice advice on the care of adults with rehabilitation needs as a result of a period of critical illness that required in-patient treatment in critical care.

Treatment and care should take into account patients' needs and preferences. People with rehabilitation needs should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals. If patients do not have the capacity to make decisions, healthcare professionals should follow the Department of Health (2001) guidelines – 'Reference guide to consent for examination or treatment' (available from www.dh.gov.uk). Healthcare professionals should also follow a code of practice accompanying the Mental Capacity Act (summary available from www.publicguardian.gov.uk).

Good communication between healthcare professionals and patients is essential. It should be supported by evidence-based written information tailored to the patient's needs. Treatment and care, and the information patients are given about it, should be culturally appropriate. It should also be accessible to people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English.

If the patient agrees, families and carers should have the opportunity to be involved in decisions about treatment and care.

Families and carers should also be given the information and support they need.

1 Summary

1.1 List of all recommendations

During the critical care stay

1.1.1 During the patient's critical care stay and as early as clinically possible.

- Perform a clinical assessment to determine whether the patient has, or is at risk of developing, physical[1] and non-physical[2] morbidity and identify current rehabilitation needs.
- Agree short-term and medium-term rehabilitation goals with the patient, where possible, based on the clinical assessment. The patient's family and/or carer[3] should also be involved.
- The clinical assessment and the short-term and medium-term rehabilitation goals should be collated and documented in the patient's clinical records.

The clinical assessment includes assessments undertaken by different professional groups in critical care. These assessments should focus on identifying the risk of developing different physical and non-physical problems, and could be carried out using locally-defined assessment tools.

1.1.2 Start rehabilitation as early as clinically possible, based on the clinical assessment and rehabilitation goals set in critical care. Rehabilitation should include:

- measures to prevent avoidable physical and non-physical morbidity

[1] Physical morbidity encompasses the following examples: muscle loss, muscle weakness, musculoskeletal problems, respiratory problems, sensory problems, swallowing and communication problems.
[2] Non-physical morbidity/problems encompass psychological, emotional and psychiatric problems, and cognitive dysfunction.
[3] During critical care stay, the patient may not gain full consciousness or may not have full capacity to give formal consent. Therefore, the involvement of family and/or carer is important at this stage.

- an individualised, structured rehabilitation programme with frequent follow-up reviews. The details of the structured rehabilitation programme and the reviews should be documented in the patient's clinical records.

Before discharge from critical care

1.1.3 Before discharging the patient from critical care.

- Re-assess whether the patient has, or is at risk of developing physical and non-physical morbidity based on the clinical assessment and the individualised structured rehabilitation programme set in critical care. The re-assessment should pay particular attention to:
  - any underlying factors, such as evidence of pre-existing psychological or psychiatric distress
  - any symptoms that have developed during the inpatient stay that may be indicative of physical and/or non-physical morbidity (such as delusional or intrusive memories, anxiety or panic episodes, nightmares or flashback episodes, depression).
- Review, agree and update the short-term and medium-term rehabilitation goals with the patient based on the re-assessment. If the patient agrees, the family and/or the carer should also be involved.
- Ensure the transfer of the patient and the formal handover of their care are in line with 'Acutely ill patients in hospital' (NICE clinical guideline 50. This should include the formal handover of the individualised structured rehabilitation programme.

During ward-based care

1.1.4 Based on the re-assessment and the agreed updated short-term and medium-term rehabilitation goals set before the patient was discharged from critical care.

- For patients who have had an ICU stay longer than 48 hours and who have received mechanical ventilatory support, provide a structured and supported self-directed rehabilitation programme[4] for at least 6 weeks after discharge from critical care.
- For other critically ill patients who have not had an ICU stay longer than 48 hours or who have not received mechanical ventilatory support, consider providing a structured and supported self-directed rehabilitation programme for at least 6 weeks after discharge from critical care.
- For patients with more complex needs, provide an individually-tailored rehabilitation programme which should be developed and delivered by appropriate members of a multidisciplinary team[5].
- For patients with symptoms of stress related to traumatic incidents and/or memories, refer to 'Post-traumatic stress disorder (PTSD)' (NICE clinical guideline 26) and initiate appropriate preventative strategies.

Before discharge to home or community care

1.1.5 Before discharging the patient to home or community care.

- Perform a functional assessment which should include the following (table 1 gives examples of physical and non-physical dimensions):

[4] The structured and supported self-directed rehabilitation programme should be coordinated by an appropriately skilled healthcare professional throughout its duration. The optimal time for starting the structured and supported self-directed rehabilitation programme should be based on individual patients' physical and cognitive capacity at different stages of their illness and recovery.

[5] A multi-disciplinary team is a team of health care professionals with the full spectrum of clinical skills needed to offer holistic care to patients with complex problems. The team may be a group of people who normally work together, or who only work together intermittently.

Physical dimensions

- physical problems
- sensory problems
- communication problems
- social care or equipment needs

Non-physical dimensions

- anxiety
- depression
- nightmares, delusions, hallucinations and flashbacks
- avoidance behaviour
- behavioural and cognitive problems
- psycho-social problems

- Assess the impact of the outcomes from the functional assessment on the patient's activities of daily living and participation.
- Based on the functional assessment, review, update and agree the short-term and medium-term rehabilitation goals with the patient. If the patient agrees, the family and/or carer should be involved.

Table 1 Examples of physical and non-physical dimensions for the functional assessment

Physical dimensions	
Physical problems	Weakness, inability to sit or to rise to standing, or to walk, fatigue, breathlessness, swallowing difficulties, incontinence, inability to self-care
Sensory problems	Changes in vision or hearing, pain, altered sensation
Communication problems	Difficulties in speaking or using language to communicate, difficulties in writing
Social care or equipment needs	Mobility aids, transport needs, housing, benefits, employment and leisure
Non-physical dimensions	
Anxiety and depression	New or recurrent somatic symptoms including palpitations, irritability, sweating; symptoms of derealisation and depersonalisation; avoidance behaviour; depressive symptoms including tearfulness and withdrawal
Behavioural and cognitive problems	Loss in memory, attention deficits, sequencing problems, deficits in organisational skills, confusion, apathy, disinhibition, compromised insight
Psycho-social problems	Low-self-esteem, poor/low self-image and/or body image issues, relationship difficulties, including family/carer

1.1.6 If continuing rehabilitation needs are identified before the patient is discharged, ensure that:

- arrangements are in place, including appropriate referrals for the necessary ongoing care before completing the discharge
- all discharge documents are completed and forwarded to the appropriate post-discharge services and the patient
- the patient, and/or the family/carer as appropriate, is aware of the discharge arrangements and understands them.

2–3 months after discharge from critical care

1.1.7 Review the patient 2–3 months after their discharge from critical care and carry out a functional re-assessment of their health (physical and non-physical[6]) and social care needs. The functional re-assessment should include the dimensions in recommendation 1.1.5.

The functional re-assessment should be carried out on a face-to-face basis in hospital or community settings. The re-assessment should be performed by an appropriately-skilled healthcare professional(s) who is familiar with the patient's critical care problems and recovery.

1.1.8 Based on the functional re-assessment at 2–3 months after the critical care discharge.

- Refer the patient to the appropriate rehabilitation or specialist services if:
  - the patient appears to be recovering at a slower rate than anticipated according to the short-term and medium-term rehabilitation goals, or
  - the patient has developed unanticipated physical and/or non-physical morbidity that was not previously identified.
- Give reassurance if the patient does not recover as quickly as they anticipated.
- If anxiety or depression is suspected, follow the stepped care model recommended in 'Anxiety' (NICE clinical guideline 22) and 'Depression' (NICE clinical guideline 23).
- If PTSD is suspected or the patient has significant symptoms of post traumatic stress, refer to 'Post-traumatic stress disorder (PTSD)' (NICE clinical guideline 26).

[6] If non-physical morbidity such as PTSD is suspected, or if the patient has significant symptoms of post-traumatic stress, anxiety or depression, a validated tool (such as UK PTSS-14 for PTSD and symptoms of post traumatic stress, or HADS for anxiety and depression) may be used.

Key principle of care

1.1.9 Coordinate all the assessments and the rehabilitation programmes throughout the patient's rehabilitation care pathway to ensure continuity of care. The coordination should be undertaken by healthcare professional(s) with the appropriate competencies[7] and contact details of the healthcare professional(s) should be provided to all patients discharged from critical care. Key elements of the coordination should involve the following.

- Ensuring that the short-term and medium-term rehabilitation goals are reviewed, agreed and updated throughout the patient's rehabilitation care pathway.
- Ensuring the delivery of the structured and supported self-directed rehabilitation programme as appropriate.
- Liaising with primary/community care for the functional re-assessment at 2–3 months after the patient's discharge from critical care.
- Ensuring that information, including documentation, is communicated as appropriate to any hospital-based or community rehabilitation services and primary care services.

Information and support needs

1.1.10 When the clinical assessment has been performed in critical care (see recommendation 1.1.1), provide the following information to the patient. The information[8] will also be provided to the patient's family/carer.

- Information about the patient's critical illness, interventions and treatments (this could be delivered through the use of ICU

[7] The healthcare professional(s) may be intensive care professional(s) or, depending on local arrangements, any appropriately trained healthcare professional(s) from a service (including specialist Rehabilitation Medicine services) with access to referral pathways and medical support (if not medically qualified).

[8] During critical care stay, the patient may not gain full consciousness or may not have full capacity to give formal consent. Therefore, the involvement of family and/or carer is important at this stage.

diaries offered to the patient when they are discharged from critical care or later, taking into account patients' wishes).

- Information about the equipment used during their critical care stay.
- Information about any possible short-term and/or long-term physical and non-physical problems which may require rehabilitation.

Deliver all the above information on more than one occasion throughout the patient's critical care stay.

1.1.11 Before the patient is discharged from critical care, provide the following information to the patient. If the patient agrees, the information will also be provided to the patient's family/carer.

- Information about the rehabilitation care pathway.
- Information about the differences between critical care and ward-based care. This should include information about the differences in the environment, staffing and monitoring levels.
- Information about the transfer of clinical responsibility to a different medical team (this includes information about the structured handover of care recommended in 'Acutely ill patients in hospital' (NICE clinical guideline 50).
- Reinforce information about possible short-term and/or long-term physical and non-physical problems which may require rehabilitation.
- Information about difficulties in sleeping, episodes of nightmares and hallucinations and the readjustment process.

1.1.12 Before the patient is discharged to home or community care, provide the following information to the patient. If the patient agrees, the information will also be provided to the patient's family/carer.

- Information about their physical recovery, based on the goals set during ward-based care.

- Information about diet and any other continuing treatments (if applicable).
- Information about how to manage activities of daily living including self-care and re-engaging with everyday life.
- Information about driving, returning to work, housing and benefits (when applicable).
- Information about local statutory and non-statutory support services, such as support groups.
- Give the patient their own copy of the critical care discharge summary.
- Give general guidance, especially to the family/carer, on what to expect and how to support the patient at home. This should take into account both the patient's needs and the family's/carer's needs.

1.2 Care pathway

During critical care

During the patient critical care stay and as early as clinically possible

- perform a clinical assessment to determine the risk of developing physical and non-physical morbidity, and to identify current rehabilitation needs.
- agree short- and medium-term rehabilitation goals.
- start rehabilitation as early as clinically possible based on the clinical assessment: include providing an individualised, structured rehab programme and measures to prevent avoidable morbidity.
- all the above should be documented in the patient's clinical records.

Before discharge the patient from critical care

- re-assessment to determine non-physical rehabilitation needs. The re-assessment should pay particular attention to: underlying factors such as evidence of pre-existing psychological or psychiatric distress, and any symptoms developed during the inpatient stay (eg: delusional or intrusive memories, anxiety or panic episodes, nightmares or flashback, depression).
- review, agree and update short- and medium-term rehabilitation goals based on the re-assessment.

Ward-based care

During ward-based care

Based on the re-assessment and the agreed updated short- and medium-term rehabilitation goals:

- provide a structured and supported self-directed rehabilitation programme for at least 6 weeks after discharge from critical care (who have had ventilation and ICU stay > 48 hours).
- consider providing the same as above for other critically ill patients (who have not had ventilation nor ICU stay > 48 hours).
- for patients with more complex needs, provide an individually tailored rehabilitation programme which should be developed and delivered by appropriate members of a multidisciplinary team.
- for patients with symptoms of stress related to traumatic incident, refer to 'Post-traumatic stress disorder (PTSD)' (NICE clinical guideline 26) and initiate appropriate preventative strategies.

Before discharge the patient to home or community care

- perform a functional assessment on physical dimensions (physical problems, sensory problems, communication problems, social care or equipment needs), and non-physical dimensions (anxiety, depression, nightmares, delusions, hallucinations and flashback, avoidance behaviour, behavioural and cognitive problems, psycho-social problems).
- Assess the impact of the functional assessment on the patient's activities of daily living.
- Review, agree and update short- and medium-term rehabilitation goals based on the functional assessment.

If continuing rehabilitation needs are identified before the patient is discharged, ensure that:

2-3 months after critical care discharge

At 2-3 months after the critical care discharge

- review the patient and carry out a functional re-assessment based on the first functional assessment. The functional re-assessment should be carried out on a face-to-face basis in hospital or community settings.
- refer the patient to the appropriate rehabilitation or specialist services if:
  - the patient is recovering at a slower rate than anticipated, or
  - the patient has developed unanticipated physical and/or non-physical morbidity that was not previously identified.
- give reassurance if the patient does not recover as quickly as they anticipated.
- if anxiety or depression is suspected, refer to the stepped care model in 'Anxiety' (NICE CG22) and 'Depression' (NICE CG23).
- if PTSD is suspected or the patient has significant symptoms of post-traumatic stress, refer to 'PTSD' (NICE CG 26).

Key principle of care

Coordinate all the assessments and the rehabilitation programmes throughout the patient's rehabilitation care pathway to ensure continuity of care. The coordination should be undertaken by healthcare professional(s) with appropriate competencies and contact details of the healthcare professional(s) should be provided to all patients discharged from critical care. Key elements of the coordination should involve the following:

- ensuring that the short- and medium-term rehabilitation goals are reviewed, agreed and updated throughout the patient's rehabilitation care pathway.
- ensuring the delivery of the structured and supported self-directed rehabilitation programme as appropriate.
- liaising with primary/community care for the functional re-assessment at 2-3 months after critical care discharge
- ensuring that information, including documentation, is

Information and support

During the critical care stay, provide information about:

- the patient's illness, interventions & treatments, equipment used, any possible short- and/or long-term physical and non-physical problems. This should be delivered more than one occasion.

Before discharge from critical care, provide information about:

- rehabilitation care pathway
- differences between critical care and ward-based care, the transfer of clinical responsibility to a different medical team
- reinforce information about any possible short- and/or long-term physical and non-physical problems
- difficulties in sleeping, episodes of nightmares and hallucinations, the readjustment process.

Before discharge to home or community, provide information about:

- physical recovery (based on the goals set)
- how to manage activities of daily living
- driving, returning to work, housing and benefits
- local statutory and non-statutory support services
- provide the patient their own copy of the critical care discharge summery

1.3 Overview

1.3.1 Critical illness: rehabilitation after a period of critical illness

More than 100,000 people are admitted into critical care units in the UK each year (ICNARC, CMP Summary Statistics) and the majority of these people (75%) survive to be discharged home. Many of these people experience significant and persistent problems with physical, non-physical (such as psychological, psychiatric or cognitive problems) and social functioning after discharge from critical care. These problems are frequently unrecognised and, when identified, may not be appropriately assessed or managed.

Rehabilitation strategies within and following discharge from critical care may help to improve patient outcomes. Such strategies may also reduce the length of stay within critical care, hospital stay after discharge from critical care, minimise hospital readmission rates and decrease the use of primary care resources. Furthermore, these strategies could help patients return to their previous level of activities sooner. The time taken to return to previous level of activities depends on the patient's critical illness and is typically between 9 and 12 months after hospital discharge, or longer.

Currently, rehabilitation strategies after a period of critical illness tend to be disease-specific and served by neuroscience, cardiac services and burns units. For general adult critical care patients who do not fall into the above specialist rehabilitation services, no alternative rehabilitation pathway currently exists.

There is evidence to suggest that multidisciplinary rehabilitation strategies, such as structured, self-directed rehabilitation programmes following critical illness can aid physical recovery and help people cope with the physical and non-physical problems associated with critical illness. The availability of rehabilitation after critical illness varies widely across the country and presently lack coordination.

There is currently no evidence-based guideline available in England and Wales that addresses the identification, timing and nature of effective rehabilitation strategies for general critical care population to manage the physical and non-physical morbidity associated with critical illness.

This short clinical guideline aims to improve the rehabilitation of adult general critical care patients. This includes providing recommendations on assessment, identification and appropriate rehabilitation strategies throughout the patient's rehabilitation care pathway. Key principle of care and information and support needs of patients and their families/carers are also addressed in this guideline. However, this guideline does not cover adult patients receiving palliative care, clinical subgroups of patients whose specialist rehabilitation needs are already routinely assessed and delivered as part of their care pathway (for example, patients who received critical care as part of an elective pathway and who did not develop an unanticipated, continuing critical illness), and in specialist areas where published guidelines already exist such as head injury, myocardial infarction and stroke.

1.3.2 The NICE short clinical guideline programme

'Critical illness: rehabilitation after a period of critical illness' (NICE clinical guideline XX) is a NICE short clinical guideline.
For a full explanation of the process, see
www.nice.org.uk/media/EBD/23/SCGProcess.pdf

1.3.3 Using this guideline

This document is intended to be relevant to healthcare professionals who have direct contact with patients in critical care areas, general medical and surgical wards, and other inpatient and community settings where rehabilitation strategies may be delivered following a period of critical illness. The target population is adults with rehabilitation needs as a result of a period of critical illness that required critical care.

This is the full version of the guideline. It is available from www.nice.org.uk/CGXX. Printed summary versions of this guideline are available: 'Understanding NICE guidance' (a version for patients and carers)

and a quick reference guide (for healthcare professionals). These are also available from www.nice.org.uk/CGXX ***[Applies to the final version of the guideline after publication]***

1.3.4 Using recommendations and supporting evidence

The Guideline Development Group (GDG) reviewed the evidence. For each clinical question the GDG was presented with a summary of the clinical evidence, and where appropriate economic evidence, derived from the studies reviewed and appraised. From this information the GDG was able to derive the guideline recommendations. The link between the evidence and the view of the GDG in making each recommendation is made explicit in the accompanying evidence to recommendations sections.

2 Evidence review and recommendations

2.1 Screening and assessment tools

2.1.1 Introduction

More than 100,000 people are admitted into critical care in the UK each year (ICNARC, CMP Summary Statistics). Patients admitted to critical care may experience physical and emotional stress, and many experience a range of significant and persistent problems with physical, non-physical (such as psychological or cognitive) and social functioning after discharge. Extended follow-up after critical care treatment has shown many patients experience long-term physical and non-physical morbidity that affect their quality of life (Broomhead and Brett 2002) This morbidity may be triggered by medication, the environment, invasive treatments such as mechanical ventilation, and sleep deprivation (Hewitt 2002).

Physical morbidity

Continuing, severe physical morbidity is well documented in patients confined to bed in critical care units. General muscle atrophy, joint pain, loss of bone mass and loss of proprioception are associated with prolonged critical illness and lengthy periods of bed rest and immobility (Ferrando AA et al. 1995; Haines R 1974; Nava 1998). The duration of critical care stay is also associated with the degree of mobility problems. The longer the period of critical illness, the more muscle patients are likely to lose (Jones and Griffiths 2000). A large follow-up study of patients with acute respiratory distress syndrome (ARDS) further confirmed that muscle weakness is the single greatest determinant of outcome and showed that the time for recovery should be measured in months to years rather than days to weeks (Herridge et al. 2003).

Some patients may also have difficulty in swallowing as a result of muscle weakness, prolonged intubation or procedures such as tracheostomy. The prevalence of swallowing dysfunction after extubation has been reported in

between 20% to 83% of those patients intubated longer than 48 hours (Leder et al. 1998; Tolep K et al. 1996).

Non-physical morbidity

In addition to any physical morbidity, treatment in critical care may be also both stressful and psychologically traumatic for patients. Studies have shown that non-physical morbidity is common in patients who survive a critical illness. Non-physical morbidity, including anxiety and depression, can last months or even years after critical care discharge. Many patients also have some symptoms indicative of post-traumatic stress phenomena (Scragg et al. 2001; Sukantarat et al. 2007), with around 1 in 10 patients having symptom scores consistent with a full diagnosis of PTSD (Jones et al. 2007). As well as psychological problems, a significant percentage of critically ill patients experience cognitive dysfunction affecting their quality of life and overall daily functioning in the longer term (Gordon SM et al. 2004). Substantial cognitive under-performance, including difficulties with problem-solving and poor memory, is a common occurrence during the first year after the critical illness (Jones et al. 2006; Sukantarat et al. 2005). These longer-term cognitive impairments have also been shown to be associated with delirium due to the multiple physiological and pharmacologic stressors that affect the central nervous system during critical illness (Hopkins and Jackson 2006).

Assessment of physical and non-physical morbidity

Despite the prevalence of physical and non-physical morbidity after critical care, it is frequently un-recognised and, even when identified, may not be appropriately assessed or managed. Optimally timed, comprehensive screening and assessment of the rehabilitation needs of critical care patients using an appropriate tool has therefore been proposed as a necessary and integral part of continuing care (Hewitt 2002). However, screening and assessing survivors of critical illness in different hospital and outpatient settings presents a variety of challenges and may require the use of specific tools. It has been suggested that critical care patients should be screened and assessed at various stages of their illness as they move from critical care to ward-based care and then to outpatient settings (Gordon et al. 2004). Thus, it

is necessary to determine the effectiveness and cost-effectiveness of any screening and assessment tools for rehabilitation needs used in this patient population.

2.1.2 Overview

We identified 116 published, individual studies based on study abstracts. After further assessment, there was one study (Collen FM et al. 1991) on the clinical/test utility of physical function screening/assessment tools for critical care populations and six studies (Beauchamp et al. 2001; McKinley and Madronio 2008; Stoll et al. 1999; Sukantarat et al. 2007; Twigg et al. 2008; Vedana et al. 2002) on the clinical/test utility of non-physical morbidity screening/assessment tools for critical care populations. No study was identified for screening and assessing swallowing and communication problems, and no specific study was identified on the optimal timing for screening or assessing physical and non-physical morbidity. However, one study (Twigg et al. 2008) on screening/assessment tools for non-physical morbidity (specifically PTSD) reported an analysis of optimal timing for screening for acute PTSD. The other 109 studies were excluded for various reasons (not relevant - 75; inappropriate population – 13; delirium - 21). All seven included studies were appraised individually using the QUADAS checklist (ref: appendix G, The Guidelines Manual. 2008 (www.nice.org.uk/guidelinesmanual) and were presented in the evidence tables and narrative summary.

Of the seven studies included, there was one cohort study (Collen FM et al. 1991) on screening/assessment tool for physical functional status (from UK rehabilitation population). Due to the lack of evidence on validated physical function screening/assessment tools within a critical care population, a descriptive summary table of instruments currently used widely in rehabilitation or physiotherapy was prepared for reference (separate document, see appendix 4).

As well as the cohort study on physical functional status, there were also two cohort studies on screening/assessment tools for PTSD (Stoll et al. 1999; Twigg et al. 2008) (one from UK, one from Germany); two studies on

screening/assessment tools for depression and anxiety (Sukantarat et al. 2007; Vedana et al. 2002) (one cross-sectional study from Italy, one cohort study from UK); one study (McKinley and Madronio 2008) on screening/assessment tool for anxiety only (cohort study from Australia); and one study (Beauchamp et al. 2001) on screening/assessment tools for cognitive dysfunction (quasi-experiment from the USA).

Overall, the evidence was of mixed quality. Three out of the seven included studies (Beauchamp et al. 2001; Collen FM et al. 1991; McKinley and Madronio 2008) need cautious interpretation as these studies were graded as low quality based on the QUADAS checklist (with level of evidence '-').

2.2 The clinical/test utility of screening/assessment tools in identifying critical care adult patients at risk of physical and non-physical morbidities.

Recommendation 1.1.1

During the patient critical care stay and as early as clinically possible.

- Perform a clinical assessment to determine whether the patient has, or is at risk of developing, physical[9] and non-physical[10] morbidity, and identify current rehabilitation needs.
- Agree short-term and medium-term rehabilitation goals with the patient, where possible, based on the clinical assessment. The patient's family and/or carer[11] should also be involved.
- The clinical assessment and the short-term and medium-term rehabilitation goals should be collated and documented in the patient's clinical records.

The clinical assessment includes assessments undertaken by different professional groups in critical care. These assessments should focus on identifying the risk of developing different physical and non-physical problems, and could be carried out using locally-defined assessment tools.

Recommendation 1.1.3

Before discharging the patient from critical care.

- Re-assess whether the patient has, or is at risk of developing physical and non-physical morbidity based on the clinical assessment and the individualised structured rehabilitation programme set in critical care. The re-assessment should pay

[9] Physical morbidity encompasses the following problems: muscle loss, muscle weakness, musculoskeletal problems, respiratory problems, sensory problems, swallowing and communication problems.

[10] Non-physical morbidity/problems encompass psychological, emotional and psychiatric problems, and cognitive dysfunction.

[11] During critical care stay, the patient may not gain full consciousness or may not have full capacity to give formal consent. Therefore, the involvement of family and/or carer is important at this stage.

particular attention to:

- any underlying factors such as evidence of pre-existing psychological or psychiatric distress
- any symptoms that have developed during the inpatient stay that may be indicative of physical and/or non-physical morbidity (such as delusional or intrusive memories, anxiety or panic episodes, nightmares or flashback episodes, depression).

- Review, agree and update the short-term and medium-term rehabilitation goals with the patient based on the re-assessment. If the patient agrees, the family and/or the carer should also be involved.
- Ensure the transfer of the patient and the formal handover of their care are in line with 'Acutely ill patients in hospital' (NICE clinical guideline 50. This should include the handover of the individualised structured rehabilitation programme.

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Recommendation 1.1.5

Before discharging the patient to home or community care:

- Perform a functional assessment which should include the following (table 1 gives examples of physical and non-physical dimensions):

  Physical dimensions

  - physical problems
  - sensory problems
  - communication problems
  - social care or equipment needs

  Non-physical dimensions

  - anxiety
  - depression
  - nightmares, delusions, hallucinations and flashbacks
  - avoidance behaviour
  - behavioural and cognitive problems
  - psycho-social problems
- Assess the impact of the outcomes from the functional assessment on the patient's activities of daily living and participation.
- Based on the functional assessment, review, agree and update the short-term and medium-term rehabilitation goals with the patient. If the patient agrees, the family and/or carer should be involved.

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Table 1 Examples of physical and non-physical dimensions for the functional assessment

Physical dimensions	
Physical problems	Weakness, inability to sit, or to rise to standing, or to walk, fatigue, breathlessness, swallowing difficulties, incontinence, inability to self-care
Sensory problems	Changes in vision or hearing, pain, altered sensation
Communication problems	Difficulties in speaking or using language to communicate, difficulties in writing
Social care or equipment needs	Mobility aids, transport needs, housing, benefits, employment and leisure
Non-physical dimensions	
Anxiety and depression	New or recurrent somatic symptoms including palpitations, irritability, sweating; symptoms of derealisation and depersonalisation; avoidance behaviour; depressive symptoms including tearfulness and withdrawal
Behavioural and cognitive problems	Loss in memory, attention deficits, sequencing problems, deficits in organisational skills, confusion, apathy, disinhibition, compromised insight
Psycho-social problems	Low-self-esteem, poor/low self-image and/or body image issues, relationship difficulties, including family/carer

Recommendation 1.1.7

Review the patient 2–3 months after their discharge from critical care and carry out a functional re-assessment of their health (physical and non-physical[12]) and social care needs. The functional re-assessment should include the dimensions in recommendation 1.1.5.

The functional re-assessment should be carried out on a face-to-face basis in hospital or community settings. The re-assessment should be performed by an appropriately skilled healthcare professional(s) who is familiar with the patient's critical care problems and recovery.

[12] If non-physical morbidity such as PTSD is suspected, or if the patient has significant symptoms of post traumatic stress, anxiety or depression, a validated tool (such as UK PTSS-14 for PTSD and symptoms of post traumatic stress, or HADS for anxiety and depression) may be used.

2.2.1 Evidence review

Physical morbidity

One low quality, cohort study on a screening/assessment tool for physical functional status was included (Collen FM et al. 1991). This cohort study was based on a rehabilitation population (patients who suffered head injury, stroke or neurosurgery) in a single rehabilitation centre in the UK. This study needs cautious interpretation as the study did not have clear inclusion/exclusion criteria, no reference standard was specified, the study population was very small (N = 23), patients were already in a rehabilitation programme when the assessment was carried out, and the study did not provide information on the critical care stay. The tool used in this study was the Rivermead Mobility Index (RMI).

The RMI is a measure of disability related to bodily mobility. It demonstrates the patient's ability to move her or his own body. However, it does not measure the effective use of a wheelchair or the mobility when aided by someone else. There are 15 items with yes (1) or no (0) answer, scores range from 0 to 15.

Validity and Reliability of the RMI:

In this study, the inter-rater reliability (Spearman's ρ) of the RMI was reported as $\rho = 0.94$ ($p < 0.001$) and the concurrent validity of the RMI (in relation to the Barthel index) was $r = 0.91$ ($p < 0.01$).

2.2.2 Evidence statement

The Rivermead Mobility Index showed good inter-rater reliability and concurrent validity for screening or assessing adult neuro-rehabilitation patients at risk of physical functional impairment. This small study is assessed as of low quality.

2.2.3 Evidence to recommendations

The GDG discussed the evidence on a screening/assessment tool for identifying physical morbidity and agreed that there was a lack of robust

evidence for the clinical/test utility of screening/assessment tools for physical function, including communication and swallowing difficulties in critical care.

The GDG recognised that there are currently a variety of tools being used in rehabilitation practice. However, most studies on these tools were based on specific populations such as head injury patients or neurological patients. The GDG also agreed that most of these tools such as the Rivermead Mobility Index (RMI), Katz's Activities of Daily Living index and Barthel index are for assessing and monitoring patients with higher levels or more severe physical, musculoskeletal or neurological problems and therefore would be unlikely to be very sensitive or specific for a general critical care population. Moreover, they are also relatively complex tools and are somewhat time consuming to perform. The GDG also recognised that some of these tools such as the Functional Independence Measure (FIM) and Functional Assessment Measure (FAM) need specialist training in using them and any recommendation to use these tools would need to recognise the associated training needs. The GDG also stressed that most of the tools only apply to the period before hospital discharge (ie. walk tests) and lack utility in the community or home settings.

The GDG came to the conclusion that these tools are not validated in general critical care populations and no one tool would be sufficient to cater for the wide variety of physical presentations observed in patients with critical illness. The GDG also agreed that while no one single formal physical screening tool could be recommended for this population, all the clinical assessments of physical morbidity could still be carried out at different stages of the patient's rehabilitation care pathway. These assessments could be completed by suitably qualified professionals using locally defined assessment tools that are suitable for the individual patient and local healthcare structure. The four key stages of a patient's rehabilitation care pathway in relation to assessment are during critical care; critical care discharge; before discharge to home/community care; and at follow-up.

Patients' rehabilitation care pathway

i) During the critical care stay

The GDG agreed that a clinical assessment (with locally defined assessment tools as discussed previously) of the patient and a quantification of their likely risk of developing physical morbidity should be undertaken as early as possible during the critical care stay. Although there is no direct evidence on the clinical effectiveness of early rehabilitation compared with late rehabilitation, the GDG generally agreed and accepted the principles that early identification, treatment and rehabilitation during critical care would potentially reduce further rehabilitation needs. The GDG also recognised the importance of negotiating and setting goals pertaining to recovery with individual patients, their families and carers. Goal setting is a central part of rehabilitation practice. This will allow progress to be monitored and may also help to avoid un-realistic expectations of recovery rates.

ii) Before discharge from critical care

The GDG agreed that a re-assessment based on previous clinical assessment (including reviewing and updating previous rehabilitation goals) to determine a patient's continuing physical rehabilitation needs ought to be performed before the patient is discharged to ward-based care:

- Firstly, to ensure that any physical morbidity not previously identified during the patient's critical care stay would be identified before discharge.
- Secondly, to ensure that any rehabilitation initiated during the critical care stay is continued when the patient is discharged to general ward-based care.

The GDG also stressed the importance of the continuity of care between critical care and general ward-based care as defined in the relevant recommendations in the NICE Acutely Ill Patients guideline (http://www.nice.org.uk/guidance/index.jsp?action=download&o=35950).

iii) Before discharge to home or community care

The GDG agreed that, in order to prepare patients to return home, a complete functional assessment (as well as assessment of physical morbidity) that assesses capacity and the help required to undertake activities of daily living

should be carried out before hospital discharge. Instead of using different formal assessment tools, the GDG agreed that the functional assessment should focus on key dimensions that are indicative of everyday functional problems. The dimensions that are included in the functional assessment (see recommendation 1.1.5) came from GDG consensus, with specific inputs from Rehabilitation Medicine Specialists, Clinical Psychologist, Nurse Consultants from critical care follow-up services, and patient representatives. The GDG also agreed that the functional assessment should be incorporated into the review and update of the rehabilitation goals previously identified and should be part of a comprehensive discharge plan. The GDG stressed that the aim is to give patients a more realistic expectation about their recovery after discharge.

iv) 2-3 months after discharge from critical care

The GDG also considered that follow-up assessment should be provided to ensure that those patients with unanticipated or delayed recovery would be supported by appropriate follow-up care or referrals back to the specialist rehabilitation care pathway. The GDG acknowledged that at this stage, a very small proportion of patients may be still in hospital (instead of recovering at home or community care settings). With specific input from the patient representatives, the GDG decided that assessment on daily physical functioning should be carried out 2-3 months after critical care discharge by suitably qualified healthcare professionals. The GDG suggested that this 2-3 months assessment should include those dimensions from the functional assessment discussed at the previous section (also see recommendation 1.1.5).

v) Key principle of care

The GDG recognised and acknowledged that the patient's rehabilitation care pathway would involve different medical teams or healthcare professional teams that came from both secondary care (critical care and hospital ward-base care) and primary care. Because of the involvement of various medical and/or healthcare professionals across different settings in assessing patients' physical morbidity, careful coordination by appropriately trained healthcare

professional(s) throughout the patient's rehabilitation care pathway is crucial to ensure continuity of care.

Non-physical morbidity

(a) Post-traumatic stress symptoms (PTS-symptoms)

Two good quality studies on screening/assessment tools for post-traumatic stress disorder (PTSD) were included. One study was a cohort study in the UK using the UK-PTSS-14 (Twigg et al. 2008) as a screening/assessment tool to identify patients at risk of suffering PTSD ICUs. The UK-PTSS-14 is a 14-item self-report screening/assessment tool; each item is rated 1 (never) to 7 (always) with a total score ranging from 14 to 98. The Posttraumatic Stress Diagnostic Scale (PDS) was used as the reference standard in this study, which corresponds to DSM-IV diagnostic criteria for PTSD. The UK-PTSS-14 was administered at 3 time-points (4-14 days, 2 months and 3 months after ICU discharge). The PDS was only administered at 3 months after ICU discharge.

Validity and Reliability of the UK-PTSS-14:

The internal reliability (Cronbach's α) of the UK-PTSS-14 was reasonably good with (at 4-14 days: α = 0.89; at 2 months: α = 0.86 and at 3 months: α = 0.84). The concurrent validity of the UK-PTSS-14 in relation to the PDS at 3 months after ICU discharge was reported as r = 0.86. The predictive validity of the UK-PTSS-14 was

- at 4-14 days after ICU discharge: r = 0.50 (95%CI: 0.24-0.69), p = 0.001; and
- at 2 months after ICU discharge: r = 0.85 (95%CI: 0.74-0.92), p < 0.0001].

After ROC analysis, time-point 2 (at 2 months after ICU discharge) had the highest AUC index = 0.95 (95%CI: 0.84-0.99) with the cut-off point of 45. The sensitivity was 86% (95% CI: 42.2-97.6) and the specificity was 97% (95% CI: 85.8-99.5). The UK-PTSS-14 was only validated in this particular study to screen acute PTSD (at 2 months after ICU discharge) but not for predicting chronic or delayed onset PTSD.

Another good quality study on screening/assessment tools for PTSD was a cohort study from Germany (Stoll et al. 1999). The study population was adult ICU patients treated for acute respiratory distress syndrome (ARDS). This study used the PTSS-10 as a screening/assessment tool for PTSD at 2 years after ICU discharge. The PTSS-10 is a 10 item self-report tool that records the presence and intensity of 10 PTSD symptoms using a scale 1 (never) to 7 (always) with total score ranging from 10 to 70. Structured clinical interview with 2 trained psychiatrists to diagnose PTSD according to DSM-IV criteria was used as reference standard for this particular study.

Validity and Reliability of the PTSS-10:

The internal reliability (Cronbach's α) of the PTSS-10 at 2 years after ICU discharge was good with α = 0.93. From the ROC curve analysis, the optimal threshold value (cut-off point) for the PTSS-10 was 35 and the maximal sensitivity/specificity at the optimal threshold were

- Sensitivity = 77% (95%CI: 54%-100%),
- Specificity = 97.5% (95%CI: 91%-100%),
- PPV = 91% (95%CI: 74%-100%), and
- NPV = 93% (95%CI: 85%-100%).

This study showed good validity and reliability of PTSS-10 as a screening/assessment tool for chronic or delayed PTSD. However, the results only applied to ICU patients with ARDS.

2.2.4 Evidence statements:

The UK-PTSS-14 showed good validity and reliability for screening or assessing adult patients who have had a critical care episode at risk of acute PTSD. This was assessed as being good quality study.

The PTSS-10 showed good validity and reliability for screening or assessing adult patients who have had a critical care episode and are at risk of chronic or delayed onset PTSD . This was assessed as being a good quality study.

(b) Depression and Anxiety

Two good quality studies on screening/assessment tools for depression and anxiety were included. One was a cross-sectional study using the Hospital Anxiety and Depression Scale (HADS) and State-Trait Anxiety Inventory (STAI-X1) (Vedana et al. 2001) as screening/assessment tools to identify patients at risk of depression and anxiety (STAI-X1 only for anxiety). The HADS is a 14 items scale with 2 subscales (HADS-D: depression 7 items and HADS-A: anxiety 7 items). Each item score is rated from 0 to 3 and the total score ranges from 0 to 21 for each subscale with a cut-off point of 9 in this study. The STAI-X1 is a 20-item tool that is used to detect anxiety. Each item score is rated from 1 to 4 with a total score ranging from 20 to 80. Different cut-off points have been proposed (Vedana et al. 2002) for male and female patients (male cut-off point = 49, female cut-off point = 55). Clinical interview by a clinical psychologist using an anxiety-depression assessment form (derived based on previous experiences of clinical psychologists) and the DSM-IV (DSM code 300.4) was used as the reference standard for this particular study. The study population was adult patients admitted to cardiac, respiratory and neuro-rehabilitation in an intensive rehabilitation centre in Italy. The assessment was carried out when patients were in rehabilitation before any follow-up.

Validity and Reliability of the HADS-D:

The validity and reliability of the HADS-D in relation to the reference standard in this study was reported as: sensitivity = 80%, specificity = 84%, PPV = 55% and NPV = 95%.

Validity and Reliability of the HADS-A and STAI-X1:

The validity and reliability of the HADS-A in this study were reported as sensitivity = 72%, specificity = 84%, PPV = 60% and NPV = 90%. While the validity and reliability of the STAI-X1 were reported as sensitivity = 52%, specificity = 99%, PPV = 93% and NPV = 86%. Further analysis of ROC on STAI-X1 with 80th percentile cut-off point instead of 90th percentile (psychologist clinical interview as reference standard) showed improved

validity and reliability [sensitivity = 76%, specificity = 84%, PPV = 61%, NPV = 91% with AUC = 0.88 (95%CI: 0.80-0.95)]. Although assessed as being of good quality, concerns were raised about the generalisability of this particular study; patients in this study were from Italy (where services are different from the UK), they were already in a rehabilitation programme and the study did not provide information on the critical care stay.

Another good quality cohort study on screening/assessment tools for depression and anxiety evaluated the Depression and Anxiety Stress scale (DASS) compared with the HADS (reference standard) (Sukantarat et al. 2007). DASS is a 42 question scale (14 for each 3 subscales: depression, anxiety, stress) with each question scored from 0 to 3. Each subscale has different cut-off points:

- DASS Depression: moderate (14-20), severe (21-27), extremely severe (28-42); and
- DASS Anxiety: moderate (10-14), severe (15-19), extremely severe (20-42).

The study population was adult patients who survived a critical illness that required more than 3 days of intensive care (including mechanical ventilation). The cut-off points of HADS used in this study were defined as:

- 7 or less = non-case;
- 8 to 10 = doubtful case; or
- 11 or more = definite case

Both DASS and HADS were administered at 3 and 9 months after ICU discharge.

Validity and Reliability of the DASS in comparison to HADS:

The internal reliability (Cronbach's α) of the DASS was reported as:

- DASS Anxiety at 3 months: α = 0.92, at 9 months: α = 0.92; and
- DASS Depression at 3 months: α = 0.92; and at 9 months: α = 0.93.

The internal reliability of the HADS (reference standard) was reported as:

- HADS-A at 3 months: α = 0.83, at 9 months: α = 0.86; and
- HADS-D at 3 months: α = 0.82, at 9 months: α = 0.86.

The concurrent validity of DASS in relation to HADS at 3 months after ICU discharge was

- DASS Depression/HADS-D: ρ = 0.734, p<0.0001; and
- DASS Anxiety/HADS-A: ρ = 0.666, p<0.0001.

The concurrent validity of DASS at 9 months after ICU discharge was

- DASS Depression/HADS-D: ρ = 0.781, p<0.0001; and
- DASS Anxiety/HADS-A: ρ = 0.767, p<0.0001.

The criterion validity (Bland & Altman plot) of DASS was also reported as:

- DASS Depression/HADS-D: r = 0.93, p < 0.0001 and
- DASS Anxiety/HADS-A: r = 0.88, p < 0.0001.

This study did not demonstrate that the DASS, with three times as many questions as the HADS, has significant advantages over the HADS in an ICU population.

As well as the two good quality studies (Sukantarat et al. 2007; Vedana et al. 2002), there was also one low quality cohort study (assessed as level '-') on the Faces Anxiety Scale (FAS) as a screening/assessment tool for anxiety alone (McKinley and Madronio 2008). The FAS is a single-item scale with 5 possible responses, ranging from a neutral face to a face showing extreme fear, and is scored from 1 to 5. The scale was on an 11x24cm card and patients were asked to point to the face representing how they felt at that time. The Spielberger State Anxiety Inventory (SAI) was used as the reference standard. The SAI is a 20-item scale with 10 items on anxiety-present and 10 items on anxiety-absent, with a 4-choice Likert scale from 'not at all' to 'very much'. The study population was patients in a multidisciplinary ICU (general, cardiothoracic, neurological) in Australia, who could interact even intermittently in order to respond to questions about their feelings and emotions, had sufficient corrected vision to see the FAS, and who were not receiving mechanical ventilatory support.

Validity of the FAS in relation to SAI:

The criterion validity of the FAS in relation to SAI was reported as ρ = 0.70 (p < 0.0005).

This study needs cautious interpretation as the main aim of the study was to identify the need for intervention to reduce anxiety during the ICU stay, not to identify longer-term rehabilitation needs (no follow-up was undertaken). The appropriateness of the reference standard used can also be questioned.

2.2.5 Evidence statements:

The HADS showed good validity and reliability for screening or assessing adult patients who have had a critical care episode and who are at risk of depression and anxiety. This was assessed as being a good quality study.

STAI-X1 showed good validity and reliability for screening or assessing adult patients who have had a critical care episode and who are at risk of anxiety. This was assessed as being a good quality study.

The DASS showed good validity and reliability for screening or assessing adult patients who have had a critical care episode and who are at risk of depression and anxiety, however, the DASS was not superior over the HADS and has 3 times as many questions as the HADS. This was assessed as being a good quality study.

The Faces Anxiety Scale showed good criterion validity for screening or assessing adult critical care in-patients who are at risk of anxiety. This was assessed as being a low quality study.

(c) Cognitive Dysfunction

One low quality study (assessed as level '-') on screening/assessment tools for cognitive dysfunction was identified. This low quality study was a quasi-experimental study (Beauchamp et al. 2001) studying the reliability of the Rancho scale and the Neurologic Intensive Care Evaluation (NICE) (derived from the Rancho scale). The study population was adult patients staying in a

946 cardiothoracic surgery ICU in the USA. There was no information on patients'
947 characteristics and inclusion/exclusion criteria to the study. Both the Rancho
948 scale and NICE are neuro-cognitive assessment tools to document the level
949 of consciousness and the level of cognitive function of patients (carried out by
950 critical care nurses through observation). The Rancho scale is a non-verbal 8
951 level scale ranging from 1 (unresponsive) to 8 (orientated) while the NICE
952 (derived from the Rancho scale) is a non-verbal 9 level scale ranging from 0
953 (absent brainstem reflexes) to 8 (orientated). There was no reference
954 standard for this study. The inter-rater reliability for the Rancho scale was ρ =
955 0.91 while the inter-rater reliability for the NICE was ρ = 0.94.

956 This study needs cautious interpretation because of the study design (no
957 reference standard) and limited data provided (i.e., limited analysis, lack of
958 information on study population).

959 In addition to studies on screening/assessment tools for cognitive dysfunction,
960 we also identified background studies that proposed an association between
961 delirium and longer-term adverse cognitive outcomes. Studies of an
962 association between delirium in patients without dementia and adverse
963 cognitive outcomes have generally been carried out in non-ICU populations
964 although data are likely to apply to ICU cohorts. For example, Francis &
965 Kapoor's study (Francis J and Kapoor WN 1992) showed that general
966 hospitalised medical patients without dementia but with delirium had a
967 significant decline in cognitive function compared with controls without
968 delirium at 2-year follow-up. Dolan et al.'s study (Dolan MM et al. 2001) also
969 suggested that hip replacement surgical patients with delirium were more
970 likely to have cognitive impairments at 2 year follow-up. Finally, in McCusker
971 et al.'s study (McCusker J et al. 2001), the results also showed that medical
972 patients with delirium had lower MMSE scores at 1 year follow-up compared
973 with controls.

974 As well as studies in general medical populations, current data also showed
975 that delirium may be the most common neuro-psychiatric condition
976 experienced by up to 80% of critically ill patients (Ely et al. 2001a; Ely et al.
977 2001b). One study (Jackson et al. 2003) that assessed delirium and cognitive

outcomes in critically ill patients found long-term cognitive impairments in one in three patients with delirium at six month follow-up. The patients in this particular study had a substantially younger mean age (mean age = 53.2 years) than in other studies cited above. This background information on delirium and cognitive impairments was further discussed among GDG members.

2.2.6 Evidence statement:

The Rancho Scale and Neurologic Intensive Care Evaluation (NICE) showed good inter-rater reliability for screening or assessing the level of consciousness and gross level of cognitive function of adult cardio thoracic patients. This was assessed as being a low quality study.

2.2.7 Evidence to recommendations

The GDG discussed the evidence identified and its generalisability and applicability to each key stage of general critical care patients' rehabilitation care pathways.

i) Evidence on PTS-symptoms, anxiety and depression

The GDG discussed the evidence on post-traumatic stress symptoms (PTS-symptoms). The GDG commented that due to the specific population in the Stoll et al's study (Stoll et al. 1999) (ARDS patients), the study of PTSS-10 did not provide evidence that the instrument would function well in a more general population. The GDG agreed that the UK-PTSS-14 (Twigg et al. 2008) had better evidence for clinical/test utility and generalisability compared with the PTSS-10.

The GDG then discussed the evidence on the utility of the Hospital Anxiety and Depression Scale (HADS) (Sukantarat et al. 2007; Vedana et al. 2002) and agreed that the DASS (Depression, Anxiety and Stress Scale) was not superior over HADS and is more complicated to use. The tools evaluated in these two included studies were designed for use in different populations to that of a critical care rehabilitation population. The GDG considered therefore that the use of such tools would potentially result in over-identification in this

population. However, HADS was considered useful especially in primary care settings but its use and interpretation should be based on clinical judgment. The GDG also agreed that the evidence on the Faces Anxiety Scale (FAS) (McKinley and Madronio 2008) was of low quality and should therefore not be used as the basis of recommendations.

ii) Evidence on cognitive dysfunction

The GDG discussed the evidence and noted that Beauchamp et al.'s study (Beauchamp et al. 2001) is of very poor quality and came to the consensus that this particular study should not be used as the basis of recommendations.

In summary, the GDG acknowledged that there was a lack of good quality evidence on the clinical/test utility of screening/assessment tools to detect and assess non-physical morbidity. However, as with discussion on physical morbidity (section 2.2.3 – Evidence to recommendations), the GDG agreed that clinical assessment by suitably qualified professionals for non-physical morbidity should also be provided at the five key stages of the patient's rehabilitation care pathway.

Patients' rehabilitation care pathway

i) During the critical care stay

No evidence was identified relating to the screening or assessment of PTS-symptoms, anxiety, depression, and cognitive dysfunction when patients were still in critical care. The GDG discussed and agreed that formal structured screening/assessment tools such as the UK-PTSS-14 and HADS would not be appropriate for patients who were still in critical care. Nevertheless, as in previous discussion on physical morbidity (see section 2.2.3 – Evidence to recommendations – i) During critical care stay), the GDG agreed that the same rationales and principles should also apply to non-physical morbidity.

The GDG also further discussed the background information on the association between delirium and longer-term cognitive impairments. Although there was a consensus regarding the importance of this issue, the GDG considered that screening and interventions for critical care patients with delirium, in order to prevent further development of longer-term cognitive

impairments, will be covered in detail in the NICE Delirium guideline (to be published in 2010) and that appropriate cross-reference should be made.

ii) Before discharge from critical care

The GDG acknowledged that there is no evidence on the use of screening and/or assessment tools for identifying 'in-hospital' critical care patients at risk of developing non-physical morbidity (except in cases of prolonged hospital stay – when the hospital stay lasts more than 1 month after ICU discharge). However, the GDG recognised that patients with psychiatric history and previous experience of traumatic events are at higher risk of developing non-physical morbidity. While the GDG agreed that no one single formal non-physical screening and/or assessment tool could be recommended, the re-assessment could still be carried by using locally defined assessment tools that are suitable for local healthcare structure (as previously discussed in section 2.2.3 – Evidence to recommendations). Therefore, the GDG came to the consensus that re-assessment (based on the previous clinical assessment during critical care stay) should be carried out and should focus on, and explore, risk factors such as evidence of pre-existing psychological or psychiatric distress; and symptoms that patients have developed during the in-hospital stay indicative of non-physical morbidity such as delusional or intrusive memories, anxiety or panic episodes, nightmares or flashback.

iii) Before discharge to home or community care

No evidence was identified for specific use of screening and/or assessment tools for non-physical morbidity before the patient is discharged to home or community care. However, the GDG discussed and agreed that the same rationales and principles as discussed in section 2.2.3 'Evidence to recommendations – iii Before discharge to home/community care' should also apply to non-physical morbidity.

iv) 2-3 months after discharge from critical care

The GDG discussed optimal timing for screening/assessing non-physical morbidity at follow-up. Although one study showed that the optimal timing for screening/assessing critical care patients at risk of developing acute PTSD is 2 months after critical care discharge (Twigg et al. 2008), the GDG was

concerned that ‘2 months after critical care discharge’ may be too restrictive as the hospital length of stay before hospital discharge could vary widely among patients. The GDG also discussed optimal timing for screening/assessing anxiety, depression and cognitive dysfunction as no evidence was identified. With specific inputs from patient representatives, the GDG came to the consensus that a more appropriate time to screen/assess the risks of developing acute PTSD, anxiety and depression, and cognitive dysfunction would be 2-3 months after critical care discharge. The GDG also suggested that this 2-3 months assessment should include those dimensions from the functional assessment discussed in the previous section (section 2.2.3 – Evidence to recommendations – iii) before discharge to home/community care - also see recommendation 1.1.5).

As avoidance is one of the key clinical symptoms of PTSD, and also taking communication problems into consideration if patients are already suffering anxiety, depression or cognitive dysfunction at home, the GDG agreed that these dimensions would be better detected or observed through face-to-face interviews.

The GDG agreed that there is no evidence to show that the use of UK-PTSS-14 and HADS in primary care or community care would improve patients’ outcomes. However, if a diagnosis of either PTSD, anxiety or depression is suspected through the list of dimensions discussed above, the GDG suggested that the use of UK-PTSS-14 and HADS may add value by enabling primary care practitioners to identify further issues, and to determine the appropriate treatment options through discussion with the patient. In this regard, it was noted that current primary care practice is to use such an assessment tool. The current Quality and Outcomes framework for the management of depression in primary care recommends that cases of depression should have an assessment of severity at the outset of treatment using an assessment tool validated for use in primary care and that the HADS is one of the recommended instruments (http://www.bma.org.uk/ap.nsf/Content/qof06~clinincalind~depression).

v) Key principle of care

As discussed in section 2.2.3 'Evidence to recommendations – v) Key principle of care', the GDG agreed that the same rationales and principles regarding coordination of the patient's rehabilitation care pathway should also apply to assessments of non-physical morbidity.

2.2.8 Health economics

The clinical and cost effectiveness of a screening and assessment tool is determined by the extent to which incorporating it into clinical practice improves health outcomes. So, in most instances, the clinical and cost effectiveness of the identification strategy will depend on whether the overall accuracy of identification is improved by its inclusion, its impact on therapeutic decisions and the effectiveness of the management strategies subsequently chosen (in this case, rehabilitation strategies). Screening and assessment tools may also assess how response might vary according to any diagnostic threshold. The diagnostic threshold then needs to be considered within the economic analysis along with outcomes for patients who may have false positive or false negative results.

Under ideal circumstances, randomised controlled trials of the screening/assessments' ability to improve long-term outcomes are required. Alternatively it may be possible to link separate pieces of information from the patient pathway.

Given the integrated nature of identification and response, the issue of cost-effectiveness in relation to these interventions is considered further in section

2.3 Rehabilitation strategies/programmes

2.3.1 Introduction

A number of critical care patients experience significant problems with physical, psychological, cognitive and social functioning for some time after critical care discharge (Department of Health 2003; HMSO London 1999). Moreover, studies also showed that quality of life after critical illness can be poor, with significant level of anxiety, depression, panic attacks and a high incidence of symptoms of PTSD (Bell and Turpin 1994; Jones et al. 1998). Rehabilitation strategies within and following discharge from critical care may help to improve patient outcomes. Such strategies may also reduce the length of stay within critical care, reduce hospital stay after discharge from critical care, minimise hospital readmission rates and decrease the use of primary care resources. Furthermore, these strategies could help patients return to their previous activities sooner.

Currently, rehabilitation strategies after a period of critical illness are not routinely provided, particularly after hospital discharge (Jones et al. 2003). However, multidisciplinary rehabilitation strategies, such as critical care follow-up clinics, are increasingly being established in a number of UK hospitals. Nevertheless, the structure, configuration and services provided by these follow-up clinics varied and were inconsistent across the country (Griffiths JA et al. 2006) and there is currently a lack of evidence on its clinical effectiveness. Hence, a systematic review of the clinical effectiveness and cost-effectiveness of different rehabilitation strategies/programmes for adult patients who have developed physical and non-physical morbidity following a period of critical illness is important. It should be associated with their treatment experience to determine which elements of care improve health outcomes for this group.

As well as rehabilitation after a period of critical illness, the new paradigm of early rehabilitation has also replaced the old paradigm which described rehabilitation as the third phase of medicine, implying that rehabilitation strategies should wait until medical and surgical stability occur (Rusk HA

1960). A number of studies have shown that early rehabilitation, beginning at a point when the patient demonstrates physiological stabilisation and continuing through the critical care stay might improve physical functioning and thus contribute to an early discharge from critical care (Bailey et al. 2007). Early identification of rehabilitation needs and early start of rehabilitation can also reduce healthcare costs by reducing dependence and nursing care, length of stay and prevention of disability (Evans RL et al. 1995; Indredavik B et al. 1991; Johnston MY et al. 2003; Kramer AM et al. 1997). Nevertheless, early rehabilitation did not uniformly occur in critical care (Thomsen et al. 2008). Hence, a systematic review on the effectiveness of early rehabilitation during critical care in reducing the subsequent risk of adult patients developing physical and non-physical morbidities following a period of critical illness is also important.

2.3.2 Overview

We identified 111 published, individual studies based on study abstracts. After further assessment, there was only one study on the clinical effectiveness of rehabilitation strategies/programmes for adult patients who have developed physical and non-physical morbidity following their critical illness and critical care treatment experience. This particular study was a randomised controlled trial based on UK population (Jones et al. 2003). No study was identified on the effectiveness of early rehabilitation during critical care in reducing subsequent risk of adult patients developing physical and non-physical morbidity; and no study was identified for the optimal time for initiating or delivering rehabilitation strategies/programmes to adult patients with physical and non-physical morbidity following a period of critical illness and associated with their treatment experience. The other 110 studies were excluded due to various reasons (not relevant - 51; inappropriate population – 4; ICU management - 32; low quality study design - 23). The included study was appraised and evaluated based on outcomes by using the modified GRADE methodology and presented in evidence table and GRADE profiles. Of the 110 excluded studies, we identified three studies that provide supporting (indirect) evidence on the effectiveness and safety of early rehabilitation during critical care in reducing subsequent risk of adult patients developing

physical and non-physical morbidity (see appendix 4). These three studies were presented separately to generate GDG discussion but not as a basis for recommendations.

2.4 The clinical effectiveness, cost-effectiveness and optimal time for the delivery of rehabilitation strategies/programmes for critical care adult patients who have developed physical and non-physical morbidity

(During the critical care stay)

Recommendation 1.1.2

Start rehabilitation as early as clinically possible, based on the clinical assessment and rehabilitation goals set in critical care. Rehabilitation should include:

- measures to prevent avoidable physical and non-physical morbidity
- an individualised, structured rehabilitation programme with frequent follow-up reviews. The details of the structured rehabilitation programme and the reviews should be documented in the patient's clinical records.

(During ward-based care)

Recommendation 1.1.4

Based on the re-assessment and the agreed updated short-term and medium-term rehabilitation goals set before the patient was discharged from critical care.

- For patients who have had an ICU stay longer than 48 hours and who have received mechanical ventilatory support, provide a structured and supported self-directed rehabilitation programme[13] for at least 6 weeks after discharge from critical care.

[13] The structured and supported self-directed rehabilitation programme should be coordinated by an appropriately skilled healthcare professional throughout its duration. The optimal time for starting the

- For other critically ill patients who have not had an ICU stay longer than 48 hours or who have not received mechanical ventilatory support, consider providing a structured and supported self-directed rehabilitation programme3 for at least 6 weeks after discharge from critical care.
- For patients with more complex needs, provide an individually tailored rehabilitation programme which should be developed and delivered by appropriate members of a multidisciplinary team[14].
- For patients with symptoms of stress related to traumatic incidents and/or memories, refer to 'Post-traumatic stress disorder (PTSD)' (NICE clinical guideline 26) and initiate appropriate preventative strategies.

(Before discharge to home or community)

Recommendation 1.1.6

If continuing rehabilitation needs are identified before the patient is discharged, ensure that:

- arrangements are in place, including appropriate referrals for the necessary ongoing care before completing the discharge
- all discharge documents are completed and forwarded to the appropriate post-discharge services and the patient
- the patient, and/or the family/carer as appropriate, is aware of the discharge arrangements and understands them.

(2-3 months after discharge from critical care)

Recommendation 1.1.8

Based on the functional re-assessment at 2–3 months after the critical care discharge.

structured and supported self-directed rehabilitation programme should be based on individual patients' physical and cognitive capacity at different stages of their illness and recovery.

[14] A multi-disciplinary team is a team of health care professionals with the full spectrum of clinical skills needed to offer holistic care to patients with complex problems. The team may be a group of people who normally work together, or who only work together intermittently.

- Refer the patient to the appropriate rehabilitation or specialist services if:
  - the patient appears to be recovering at a slower rate than anticipated according to the short-term and medium-term rehabilitation goals, or
  - the patient has developed unanticipated physical and/or non-physical morbidity that was not previously identified.
- Give reassurance if the patient does not recover as quickly as they anticipated.
- if anxiety or depression is suspected, follow the stepped care model recommended in 'Anxiety' (NICE clinical guideline 22) and 'Depression' (NICE clinical guideline 23
- if PTSD is suspected or the patient has significant symptoms of post traumatic stress, refer to 'Post-traumatic stress disorder (PTSD)' (NICE clinical guideline 26).

(Key principle of care)

Recommendation 1.1.9

Coordinate all the assessments and rehabilitation programmes throughout the patient's rehabilitation care pathway to ensure continuity of care. The coordination should be undertaken by healthcare professional(s) with the appropriate competencies[15] and contact details of the healthcare professional(s) should be provided to all patients discharged from critical care. Key elements of the coordination should involve the following.

- Ensuring that the short-term and medium-term rehabilitation goals are reviewed, agreed and updated throughout the patient's rehabilitation care pathway.
- Ensuring the delivery of the structured and supported self-directed rehabilitation programme.

[15] The healthcare professional(s) may be intensive care professional(s) or, depending on local arrangements, any appropriately trained healthcare professional(s) from a service (including specialist Rehabilitation Medicine services) with access to referral pathways and medical support (if not medically qualified).

- liaising with primary/community care for the functional re-assessment at 2-3 months after the patient's discharge from critical care.
- ensuring that information, including documentation, is communicated as appropriate to any hospital-based or community rehabilitation services and primary care services.

2.4.1 Evidence review

Only one study was included in the review of the clinical effectiveness of different rehabilitation strategies/programmes for adult patients who have developed physical and non-physical morbidity, including psychological problems and cognitive deficits, following a period of critical illness and associated with their treatment experience in critical care. The study was a UK based study from Jones et al (Jones et al. 2003) on the effectiveness of a 6-week supported self-help rehabilitation manual. The patient population of the Jones et al. (2003) study was adult patients in three UK ICUs who had stayed more than 48 hours and were ventilated.

In this particular study, the intervention was the use of a 6-week supported self-help rehabilitation manual plus 'usual care' at baseline (which was defined as at critical care discharge). The 6-week supported self-help rehabilitation manual included 93 pages of text, diagrams and supporting illustrations; advice on psychological, psychosocial and physical problems; a self-directed exercise programme; 3-weekly telephone calls to reinforce the use of the manual; ensuring patients kept a diary about the use of the manual; and the involvement of a close relative or friend of their choosing. On the other hand, control or 'usual care' in the study was defined as routine ICU follow-up, including 3 telephone follow-ups at the patient's home and ICU follow-up clinic appointments at 8-weeks and 6-months after ICU discharge. Data were collected for analysis at baseline, 8-week and 6-month follow-up.

Summary of GRADE profiles (Jones et al. 2003) (for full GRADE profiles, see appendix 4):

		Summary of findings				
		No. of patients		Effect		
No. of studies	Design	Intervention[1]	Control[2]	Relative (95%CI)	Absolute	Quality
Physical function[3] (at 3 time-points: baseline, 8 weeks, 6 months after ICU discharge)						
1	RCT	58	44	ANOVA (at 3 time-points interaction) F = 3.7, p = 0.006		Moderate
Physical function[3] (at 8 weeks after ICU discharge)						
1	RCT	63	51	Univariate ANOVA (at 8 weeks) F = 12.19, p < 0.0001		Moderate
Physical function[3] (at 6 months after ICU discharge)						
1	RCT	58	44	Univariate ANOVA (at 6 months) F = 14.4, p < 0.0001		Moderate
Depression[4] (at 8 weeks after ICU discharge)						
1	RCT	8/63 (12%)	13/51 (25%)	0.4981 (0.2239, 1.1082)	13%	Moderate
Depression[4] (at 6 months after ICU discharge)						
1	RCT	6/58 (10%)	5/44 (12%)	0.9103 (0.2696, 2.7908)	2%	Moderate
Anxiety[5] (at 6 months after ICU discharge)						
1	RCT	19/58 (32%)	15/44 (34%)	0.9609 (0.5532, 1.6689)	2%	Moderate
PTSD-related symptoms[6] (at 8 weeks after ICU discharge)						
1	RCT	63	51	1-way ANOVA (at 8 weeks) F = 5.24, p = 0.026		Moderate

1 Intervention: 6-week self-help rehabilitation manual

2 Control: Usual care defined as: routine ICU follow-up included 3 telephone follow-ups at home; ICU follow-up clinic appointments at 8 wks and 6 months.

3 Physical function was measured by SF-36 physical function score.

4 Depression was measured by HADS-D, with cut-off >11 as cases.

5 Anxiety was measured by HADS-A, with cut-off >11 as cases.

6 PTSD-related symptoms were measured by IES.

2.4.2 Evidence statements:

A 6-week supported self-help rehabilitation manual improved the recovery of patients' physical function eight weeks and six months after ICU discharge. This was assessed as being moderate quality evidence.

A 6-week supported self-help rehabilitation manual did not improve patients' levels of depression eight weeks and six months after ICU discharge. This was assessed as being moderate quality evidence.

A 6-week supported self-help rehabilitation manual did not improve patients' levels of anxiety six months after ICU discharge. This was assessed as being moderate quality evidence.

A 6-week supported self-help rehabilitation manual reduced patients' PTSD-related symptoms eight weeks after ICU discharge but not at six months. This was assessed as being moderate quality evidence.

No study was identified on the effectiveness of early rehabilitation during critical care in reducing subsequent risk of adult patients developing physical and non-physical morbidity; and no study was identified for the optimal time for initiating or delivering rehabilitation strategies/programmes to adult patients with physical and non-physical morbidity following a period of critical illness and associated with their treatment experience. From the excluded studies, three studies were identified as supporting (indirect) evidence (they were excluded due to inappropriate population) on the effectiveness and safety of early rehabilitation during critical care in reducing subsequent risk of adult patients developing physical and non-physical morbidity - two RCTs (Chiang et al. 2006; Galle et al. 2007); and one cohort study (Bailey et al. 2007). The Chiang et al's study (Chiang et al. 2006) showed that early supervised physical training when patients were still in a Taiwan respiratory care centre improved physical function six weeks after intervention in patients who had prolonged mechanical ventilation (more than 14 days) compared with those who did not start the supervised physical training early. The Galle et al's study

(Galle et al. 2007) also showed that early exercise in a Belgium ICU (patients with ventilation > 5 days) improved patients' physical function at hospital discharge. Finally, the Bailey et al's study (Bailey et al. 2007) showed that early mobilisation in a US respiratory ICU is feasible and safe for respiratory failure patients. These three studies were summarised and presented separately to generate GDG discussion but not as a basis for recommendations (evidence table see appendix 4).

2.4.3 Evidence to recommendations

The GDG acknowledged that there was a lack of good quality evidence for the optimal timing and clinical effectiveness of different rehabilitation strategies/programmes for adult patients who have developed physical and non-physical morbidity following a period of critical illness and associated with their treatment experience in critical care. The GDG discussed the only study that was included (Jones et al. 2003) and agreed that it is a moderate quality study. However, in Jones et al's study, the 6-week supported self-help rehabilitation manual was only shown to improve the recovery of patients' physical function but not their psychological problems; and the evidence only applies to rehabilitation initiated 1-2 weeks after critical care discharge. The study also showed that patients with delusional memories, in both study groups, had higher HADS anxiety scores at 6 months than those without delusional memories. Despite the lack of evidence, the GDG agreed that consensus recommendations on good practice regarding rehabilitation should be made at each key stage of the patient's rehabilitation care pathway where recommendations of screening and/or assessment have been suggested. This is to ensure that appropriate treatment of identified needs is provided for those patients who have been identified as at risk.

Patients' rehabilitation care pathway

i) During the critical care stay

The GDG acknowledged that there is no evidence on the clinical effectiveness of rehabilitation strategies/programmes for patients who were still in critical care, and evidence from Jones et al.'s study (Jones et al. 2003) is not applicable to this population as rehabilitation strategy in this particular study

started after intensive care (ICU) discharge (intensive care is part of critical care). However, the GDG discussed the supporting (indirect) evidence from the three excluded studies - two RCTs (Chiang et al. 2006; Galle et al. 2007); and one cohort study (Bailey et al. 2007) on the feasibility and safety of early mobilisation and generally agreed the principle of early rehabilitation in critical care. Hence, the GDG came to the consensus that recommendations on good practice should be made regarding starting rehabilitation as early as clinically appropriate based on the clinical assessment and short-term and/or long-term rehabilitation goals as discussed in section 2.2.3 'Evidence to recommendations – i) During critical care stay'. The GDG also agreed that measures to prevent avoidable morbidity should also be in place for patients in critical care.

ii) During ward-based care

The GDG further discussed the Jones et al.'s study (Jones et al. 2003) and agreed that recommendations should be made for patients after critical care discharge based on the evidence and suggested that in-patients who undergo ventilation (with ICU stay greater than 48 hours) should receive a structured and supported self-directed rehabilitation programme for at least the first six weeks following their ICU discharge. The GDG also considered that the same principles of care from Jones et al.'s study should also be applied to other critically ill patients who do not fall into the greater 48 hours ICU stay category based on individual clinical assessment. This is to ensure that for those patients who have been assessed as having physical or non-physical morbidity but had not been staying in ICU for longer than 48 hours would still have appropriate individualised follow-up rehabilitation. Nevertheless, the GDG acknowledged that the initiation and the duration of the structured and supported self-directed rehabilitation programme should be based on individual patients' physical and cognitive capacity at different stages of their illness and recovery.

Moreover, the GDG also agreed that recommendations on good practice for patients with a higher spectrum of severity should also be suggested. Therefore, the GDG came to the consensus that for patients with more

complex needs, an individualised programme should be specially created and delivered by appropriate members of a Multi Disciplinary Team (MDT). The multi-disciplinary team is a group of people from different disciplines who share their knowledge and skills or experience to address a common purpose. The team may be a group of people who normally work together, or who only work together intermittently. In the case of a patient on the critical care rehabilitation pathway, the GDG envisaged that there would be a 'core team' for each setting (for example the ward staff; primary care team) with other members joining intermittently, for example therapists, psychologists, social workers. A key point of recommending an MDT was that ensuring co-ordination carries across the boundaries would pull in the various disciplines as needed, and would help monitor the process.

The GDG also came to the consensus that if patients are identified as having any symptoms of stress related to traumatic incidents and/or memories (including the critical care experience), preventative strategies recommended in the NICE PTSD guideline should be instituted.

iii) Before discharge to home or community care

The GDG discussed what interventions should be suggested if patients are identified as having rehabilitation needs through the functional assessment before discharge to home/community care. Again, since there is a lack of evidence, the GDG felt that they could not generate any specific recommendations on rehabilitation strategies. Nevertheless, the GDG agreed that consensus recommendations on good practice should be suggested in order to ensure continuity of care from hospital to home/community settings. Hence, the GDG came to the consensus that three elements of good practice should be recommended at hospital discharge which are: to ensure appropriate arrangements are in place for patients before hospital discharge is complete; to ensure the discharge documents are forwarded to appropriate community care services; and finally to ensure patients and their family or carers are aware and understand all these arrangements.

iv) 2-3 months after discharge from critical care

As in the discussion above, the GDG discussed what interventions should be suggested if patients are identified as still having rehabilitation needs through the 2-3 months assessment after critical care discharge. Again, although there is a lack of evidence, the GDG felt that consensus recommendations on good practice should be suggested in order to ensure continuity of care. The GDG came to the consensus that if patients still have rehabilitation needs at 2-3 months, referrals to appropriate rehabilitation or specialist services should be in place including appropriate cross-references to other NICE guidelines such as the NICE Depression, NICE Anxiety and NICE PTSD guidelines.

v) Key principle of care

As discussed in section 2.2.3 'Evidence to recommendations – v) Key principle of care' the GDG agreed that the same rationales and principles regarding coordination of the patient's rehabilitation care pathway should also apply to the initiation and/or the delivery of rehabilitation. This is because the duration and provision of the structured and supported self-directed rehabilitation programme needs careful coordination as well as appropriate referrals or initiation of the intervention process based on other related NICE clinical guidelines such as the NICE Depression, NICE Anxiety and NICE PTSD guidelines.

2.4.4 Health economics

Published health economic literature

Given that identification and response should ideally be considered as an integrated decision problem, a systematic review of the literature was conducted to identify evidence on the cost effectiveness of both screening/assessment tools and associated alternative rehabilitation interventions for patients at risk of physical functional impairment, psychological problems and cognitive dysfunction. The review also attempted to identify evidence on the optimal timing of these identification/response strategies. The review identified no cost effectiveness studies on screening/assessment tools that specifically examined the cost effectiveness of screening tools for the identification of rehabilitation needs or their optimal

timing. In addition no studies were identified that specifically examined the cost effectiveness of rehabilitation as an intervention. The majority of the studies identified were on quality of life and survival or they were costing studies or review papers. None of these studies compared a rehabilitation intervention with standard care.

The PRACTICAL study is an ongoing randomised controlled trial with the aim of assessing the effectiveness and cost-effectiveness of intensive care follow-up programmes in improving physical and psychological quality of life in the year after intensive care discharge compared with standard care in the UK. The trial protocol (Cuthbertson et al, results will be reported at the end of January 2009) (Cuthbertson et al. 2007) indicates that resource use will be estimated for study participants based on patient questionnaires and the review of hospital notes. The EQ-5D questionnaire is being administered in this study, the results of which will be used in the estimation of quality-adjusted life years (QALYs). It is not known when this study is expected to report.

The clinical review on rehabilitation strategies found only one relevant trial (Jones et al. 2003). A GDG member noted that the trial protocol for this study indicated that an economic evaluation would be undertaken. An unpublished trial-based cost-utility analysis (Centre for Health Planning and Management 2001) was identified and provided to the guideline developers for consideration. A full review of this report was carried out and a data extraction table is provided in appendix 5.

The economic analysis compared the cost-effectiveness of introducing an information booklet on rehabilitation against usual care where patients are discharged with no special information. The booklet was given to the intervention group following a 20 minute discussion with a dedicated nurse. The control group was discharged from hospital following the standard hospital protocol with no additional information being given to the patient. Both groups received a follow up telephone call at weeks 2, 4 and 6. The analysis was undertaken from an NHS and PSS perspective and had a time horizon of 6 months. Although data were collected throughout the trial period, the

economic analysis concentrated on the period from when patients were given the intervention until the 6 month follow-up. Modelling to examine the result of lifetime extrapolation of costs and benefits was not carried out.

All relevant effectiveness data collected in the trial were used in this study. However, while the economic evaluation reported that the EQ-5D instrument had been used as part of the clinical trial, the Jones et al publication (Jones et al. 2003) makes no mention of this tool, and only SF-36 results are presented. Utilities in the economic evaluation were estimated from EQ-5D scores collected at various time points in the trial: at baseline (patients were asked to provide assessment on their pre illness state), 2 months and 6 months post discharge. It is not clear how the baseline assessment was taken and the change in EQ-5D scores over time was not considered in the economic evaluation, only scores at the 6 month follow-up. At 6 months, health state utility fell from 0.77 (baseline) to 0.68 (at 6 months) in the intervention group. A fall was also seen at 6 months for the control arm (0.71 to 0.66). The authors reported that there were no statistically significant differences in EQ-5D scores between the groups at baseline or at 6 months follow-up, although no further statistical information (confidence intervals, p values, and so on) was provided.

Costs were estimated using resource use data collected from patients in the clinical trial. Social and other local authority services data were obtained for each patient from the appropriate social services department and information elicited directly from patients at outpatient follow-up was supplemented by hospital records. The costs of the rehabilitation package and its administration, plus costs associated with hospital readmissions, other hospital contacts (outpatient appointments, inpatient costs and accident and emergency costs), primary and secondary care contacts and social services provision were included. The mean total costs for the intervention and control groups were £958 and £928 respectively (£1226 and £1188). The differences in costs between the intervention and control group were reported as not significant. No further statistical information on these data was reported.

Total quality adjusted life years (QALYs) were reported for the intervention and control groups at 6 months. Total QALYs appear to be estimated by multiplying the mean health state utility value at 6 months by the total number of patients in each group. Total QALYs for the intervention and control groups were reported as 20.54 and 15.65 respectively. The authors reported that the cost-effectiveness ratio of providing a booklet compared with the control was £940 per QALY gained (£12041). This estimate was calculated by using the total costs and total effectiveness for each group. However, the ICER should be calculated using the incremental differences in costs and effectiveness per patient in this case as the number of patients in each group differs. Therefore, based on the data considered in this study, the ICER may be lower than reported. Further detail is required on how QALYs were calculated in order to assess the accuracy of the reported ICER. Sensitivity analysis was not carried out on the results, and consequently no quantitative information is available of the uncertainty of the estimates.

It is important to note that in this study, patients in both the intervention and control groups had visits to a dedicated follow-up clinic. This may not be considered standard care across the UK. According to Griffiths et al.'s study (Griffiths JA et al. 2006), only 30% of units surveyed within the UK ran a dedicated rehabilitation follow up clinic. Follow up phone calls were also made to both the intervention and control groups at 2, 4 and 6 weeks which would not usually be given, this was to ensure that the groups had equal contact (due to any possible therapeutic effect of the phone calls associated with the intervention group). Costs were appropriately applied, but this meant that the control group was elevated in terms of care given compared with standard care in the UK health care setting.

The short follow up time in this evaluation may limit the usefulness of these results. Neither costs nor outcomes (in terms of EQ-5D scores) were statistically significantly different between the intervention and control groups. A power calculation was not detailed in the report and therefore it is not clear whether the study included enough patients to demonstrate a difference in economic outcomes.

De novo cost effectiveness analysis

A paucity of evidence, particularly with regard to screening/assessment methods, has meant that no de novo economic analysis was undertaken for this guideline.

Due to the number of alternative rehabilitation strategies for patients, economic evaluation of the complete identification and treatment pathway could be very complex. Inclusion of both physical and non-physical aspects would also have to be addressed and a decision taken as to whether both can be included. It is also difficult to define standard practice and main comparators in this area given variation in current clinical practice and the provision of rehabilitation follow up clinics (Griffiths JA et al. 2006).

It may be possible that a costing exercise could have been carried out to assess the impact of a particular rehabilitation strategy compared with standard care. It is sometimes useful to outline potential costs for various strategies that could be implemented. However, in this case, the issue of choosing a rehabilitation strategy and of what constitutes standard care remains. It is unknown what resource use is likely to be required as it is currently highly variable.

The health economic systematic review yielded no economic evaluations on specific rehabilitation strategies or their timing. This is likely to be due to inadequate RCT evidence on the effectiveness of rehabilitation interventions. No observational studies were identified in the clinical review.

2.4.5 Health economics evidence to recommendations

The GDG recognised the paucity of evidence relating to the clinical and cost effectiveness of the interventions covered by this guideline. The GDG noted the absence of robust data on screening/assessment strategies and that only one study was identified on the effectiveness of a rehabilitation intervention (Jones et al. 2003). This study nevertheless has a number of limitations. For example, the GDG recognised that standard care included follow-up visits at an ICU rehabilitation clinic. Therefore the control arm could not be said to be represent standard UK practice.

The GDG considered the evidence from the unpublished trial-based cost-utility analysis based on the study by Jones et al (Jones et al. 2003). The evidence from that study appears to suggest that the intervention arm was highly cost effective. However, it was the GDG's view that the data were insufficient to actually demonstrate a difference between the two alternatives. Nevertheless, benefits of the self help manual were shown in the clinical trial and these included improvement of patients' physical function at eight weeks and six months after ICU discharge and reduction of patients' PTSD-related symptoms at eight weeks (although this was not demonstrated at six months post discharge). Despite the limitations of the economic evaluation, the GDG considered it likely that the additional costs of including a patient information booklet would be small, and therefore it is probable that a 6 week self help manual is a cost effective option for rehabilitation.

2.5 Information and support needs

2.5.1 Introduction

Patients being treated in a critical care area will be recovering from a serious illness and will have been dependent on the care provided by healthcare professionals and the support of their families/carers throughout their journey towards recovery. Research has suggested that the care of a critically ill patient is not complete without some considerations of the psychological consequence(s) of the illness, and this also has implications for both the patient and his/her family/carer (Jones and O'Donnell 1994).

Studies have shown that patients are exposed to a number of stressors when they are admitted to critical care. For example, the inability to control or predict events (Jones and O'Donnell 1994); unmet informational and emotional needs (Benzer H et al. 1983); an uncertain prognosis; unfamiliar environment; medical interventions; and the inability to communicate effectively (Pennock et al. 1994). Many patients also have little or no recall of events during their stay in critical care (Saarmann L 1993; Sawdon et al. 1995; Stanton 1991), while others have vivid recollections of their stay (Green

A 1996), and as a result experience disturbing dreams, sleep deprivation and anxiety.

The Government's 'National Strategy for Carers' (Anon 2003) also recommends that services should recognise carers' individual needs, and that carers have the right to expect the NHS to help them to maintain both their physical and mental health. A study by Gillis (Gillis CL 1984) has shown that at time of admission to critical care, family members or carers can sometimes experience higher levels of stress than the patient. Other studies have also shown that families/relatives face a considerable burden and experience a number of potential stressors when caring for the patient (Plowright CI 1996), all of which could cause anxiety and depression (Young et al. 2005); or post-traumatic stress disorder-related symptoms (Jones et al. 2004).

There are also studies that showed the use of patient diaries is an effective method to deliver information for both the patient and their families/carers. For example, Backman & Walther's study (Backman and Walther 2001) has shown that ICU diaries are useful tools in the debriefing process for both patients and their families/carers following intensive care. In Bergbom et al's study (Bergbom et al. 1999), the findings also showed that the use of ICU diaries had helped patients to reconcile themselves to reality, gain a clearer and more realistic insight into the period of their severe illness or injury. Another study by Roulin et al (Roulin et al. 2007) also showed that the use of ICU diaries was very beneficial for the patients and it helped them to understand their intensive care stay and come to terms with their illness.

It is therefore relevant to consider what elements of information and support are viewed as important by adult patients and their families/carers during and following a period of critical illness. This is to ensure patient- and family/carer-centred continuity of care throughout the patient's care pathway and to minimise any potential stressors for both patients and their families/carers.

2.5.2 Overview

We identified 57 published studies from the study abstracts. After further assessment, four studies were assessed as addressing elements of

information and support viewed as important by adult patients and their families/carers during, and following, a period of critical illness requiring critical care. The remaining studies were excluded due to various reasons (not relevant – 15 studies; inappropriate population – 38 studies). To supplement the published data, we also identified two relevant modules from the UK Database of Individual Patient Experiences (DIPEx), which is available through open access (http://www.healthtalkonline.org/other_conditions/intensive_care and http://www.healthtalkonline.org/other_conditions/intensive_care_experiences_of_family_friends). DIPEx is a charity-run website aimed at patients, their carers, family and friends, doctors, nurses and other health professionals. Their aim is to cover patients' experiences of 100 important illnesses and conditions, as well as covering areas such as immunisation, rare diseases, skin conditions, infertility, chronic illness. Each of the DIPEx modules is collected and analysed by an experienced and trained researcher specialising in qualitative research. To make sure that a wide range of experiences and views are included a method called purposive (or maximum variation) sampling is used. They collect interviews until they are convinced that they have represented the main experiences and views of people within the UK. Often this requires between 40 and 50 interviews (40 patients were interviewed for the intensive care module and 38 families/carers were interviewed for the relatives of people in intensive care module).

All five included studies, including the DIPEx modules, were conducted in a critical care population in the UK. All five studies used a qualitative study design and were appraised individually using the NICE qualitative studies checklist (NICE Clinical Guidelines Manual 2008 – draft). The evidence was presented in evidence tables and a narrative summary.

Overall, the quality of the evidence was assessed as being of good quality. Two out of the five included studies were graded as '++' based on the NICE qualitative studies checklist (DIPEx) and (Strahan and Brown 2005) and the other three included studies were graded as '+' (Combe 2005; McKinney and Deeny 2002; Paul et al. 2004). Three excluded non-UK studies on patient

diaries were also summarised as supporting evidence (in separate document) for GDG discussion.

2.6 The specific information and support needs of adult patients and/or their families/carers who have developed rehabilitation needs during or following a period of critical illness

Recommendation 1.1.10

When the clinical assessment has been performed in critical care (see recommendation 1.1.1), provide the following information to the patient. The information[16] can also be provided to the patient's family/carer.

- Information about the patient's critical illness, interventions and treatments (this could be delivered through the use of ICU diaries offered to the patient when they are discharged from critical care or later, taking into account patients' wishes).
- Information about the equipment used during their critical care stay.
- Information about any possible short-term and/or long-term physical and non-physical problems which may require rehabilitation.

Deliver all the above information on more than one occasion throughout the patient's critical care stay.

Recommendation 1.1.11

Before the patient is discharged from critical care, provide the following information to the patient. If the patient agrees, the information will also be provided to the patient's family/carer.

- Information about the rehabilitation care pathway.

[16] During critical care stay, the patient may not gain full consciousness or may not have full capacity to give formal consent. Therefore, the involvement of family and/or carer is important at this stage.

- Information about the differences between critical care and ward-based care. This should include information about the differences in the environment, staffing and monitoring levels.
- Information about the transfer of clinical responsibility to a different medical team (this includes information about the structured handover of care recommended in 'Acutely ill patients in hospital' (NICE clinical guideline 50).
- Reinforce information about possible short-term and/or long-term physical and non-physical problems which may require rehabilitation.
- Information about difficulties in sleeping, episodes of nightmares and hallucinations and the readjustment process.

Recommendation 1.1.12

Before the patient is discharged to home or community care, provide the following information to the patient. If the patient agrees, the information should will be provided to the patient's family/carer:

- Information about their physical recovery, based on the goals set during ward-based care.
- Information about diet and any other continuing treatments (if applicable).
- Information about how to manage activities of daily living including self-care and re-engaging with everyday life.
- Information about driving, returning to work, housing and benefits (when applicable).
- Information about local statutory and non-statutory support services such as support groups.
- Give the patient their own copy of the critical care discharge summary.
- Give general guidance, especially to the family/carer, on what to expect and how to support the patient at home. This should take into account both the patient's needs and the family's/carer's needs.

2.6.1 Evidence review

All five included studies were set in the UK. The DIPEx (critical care modules) collected the experiences and views of critical care adult patients (http://www.healthtalkonline.org/other_conditions/Intensive_care) and their families/carers (http://www.healthtalkonline.org/other_conditions/Intensive_care_experiences_of_family_friends) throughout their treatment journey, from admission to critical care through to recovery at home. A total number of 40 adult patients and 38 families/carers were recruited in the study. Data were analysed and grouped under different topic summaries.

The study from Strahan and Brown (Strahan and Brown 2005) collected the experiences and views of 10 adult patients following transfer from critical care. The study focused on examining patients' experiences immediately following discharge to wards and their views on information and support needs perceived as important, before and after the transfer, in order to prevent stress or development of further psychological problems.

The other two studies from McKinney & Deeny (McKinney and Deeny 2002) and Paul et al (Paul et al. 2004) focused on examining patients' experiences, views, and information needs upon transfer from critical care to ward-based care. McKinney & Deeny's study (McKinney and Deeny 2002) collected data from 6 adult critical care patients during the 48 hours following transfer from the intensive care unit. The study aimed to examine patients' views on information needs and elements of support/care that were important to reduce transfer stress and to prevent later development of psychological problems. Paul et al.'s study (Paul et al. 2004) collected data from seven adult critical care patients and two families/carers. The study aimed to identify the information needs of patients and families/carers in order to construct an information booklet.

The final study (Combe 2005) examined the experiences and views of 35 critical care patients about the use of patient diaries in an intensive care unit. All results from the five included studies were summarised using thematic

analysis and presented in the table below (table 2). The results are grouped by key stages of the patient's care pathway.

1775 **Table 2: Summary of findings**

During critical care	Study
Information at different stages of illness and recovery. The elements of information needs, for example:	(DIPEx)
• Basic information on the illness, the treatments and what had happened (this could be delivered by the use of ICU diaries)	(Combe, 05)
• Information on weakness and muscle loss	(DIPEx)
• Information on likely hospital length of stay and recovery	(DIPEx)
• To have all the above information repeated again and again	(DIPEx)
• Information on equipment used	(DIPEx)
• Involvement of family/carers in sharing the information	(DIPEx)
Before critical care discharge & during ward-based care	
1. Information on and a discussion from health care professionals regarding what happened in ICU and all possible related ICU syndromes. The elements of information and support needs, for example:	(DIPEx), (Strahan et al, 05)
• Information on and reassurance regarding dreams and hallucination.	(DIPEx), (Strahan et al, 05)
• This could be delivered by the use of ICU diaries.	(Combe, 05)
Other elements, for example:	
• Digestion – feelings of sickness, nausea, lack of appetite, bowel complications.	(Strahan et al, 05)
• Mobility – lack of mobility.	(Strahan et al, 05)
• Reassurance on possible negative feeling such as anxiety, loneliness, depression and exhaustion.	(Strahan et al, 05)
• Pain.	(McKinney et al, 02)
2. Information and discussion on patient's care pathway.	(DIPEx)
3. Information and support on setting goals for physical recovery. The elements of information and support needs, for example:	(DIPEx)
• Patients' own critical illness and explanation on recovery.	(Strahan et al, 05)
4. Discuss details of transfer (from critical care to ward-based care) with patients and their family/carers.	(Paul et al, 04)
5. Briefing or information on the differences between ICU and the ward (prior to transfer). The elements of the briefing, for example:	(McKinney et al, 02)
• Differences in the physical environment.	(McKinney et al, 02), (Paul et al, 04)
• Differences in staffing levels.	(McKinney et al, 02), (Paul et al, 04)
• Differences in monitoring levels.	(McKinney et al, 02)
Before discharge to home/community care	
1. Information and discussion on discharge plan prior to hospital discharge. The elements of information and support needs, for example:	(DIPEx)
• Information on who decided the discharge and on what basis	(DIPEx)
• Information on the trajectory projection of the recovery	(DIPEx)
• Basic information on diet, exercise and drug treatment if applicable	(DIPEx)
• All the above information to be shared with family/carers	(DIPEx)
• Information for family/carers on what to expect when a person returns home after being critically ill in ICU	(DIPEx)
• To be given the ICU diaries at hospital discharge, if not been given at ICU discharge.	(DIPEx)
2. Support to prepare patients to go home. Elements of support needs, for example:	(Paul et al, 04)
• Discussion on support services available	(Paul et al, 04)
• Discussion on rehabilitation	(Paul et al, 04), (DIPEx)

• Details on sources of further help	(Paul et al, 04), (DIPEx)
Home or community care (recovering at home)	
1. Information on physical recovery and impact on daily living	(DIPEx)
2. Information on and discussion of emotional aspects of recovery: The elements of information and discussion, for example:	(DIPEx)
• Discussion on any non-physical morbidity	(DIPEx)
• Information on referrals or other voluntary support group	(DIPEx)

2.6.2 Evidence statements:

Before critical care discharge and during ward-based care, patients and their families/carers identified three important elements of information and support needs:

- *Information on sleep, hallucination, digestion, mobility, pain and reassurance on possible negative emotions.*
- *Information and discussion on patient's care pathway including support on setting goals for physical recovery.*
- *Information and discussion on details of transfer with both patients and their families/carers including the differences between critical care and ward-based care such as physical environment, staffing levels and monitoring levels.*

Before discharge to home or community care, patients and their families/carers identified three important elements of information and support needs:

- *Information and discussion on the discharge plan prior to discharge. The discharge plan should include the physical recovery rates and basic information on diet, exercise and drug treatment if applicable.*
- *Support to prepare patients to go home including discussion on support services available, rehabilitation and sources of further help.*
- *To share all information with families/carers and to provide information on what to expect when a patient returns home.*

During recovery at home/community care, patients and their families/carers identified four important elements of information and support needs:

- *discussion on physical recovery*

- *impact on daily living*
- *non-physical morbidity*
- *availability and how to access other statutory and non-statutory supportive services such as charity support groups*

2.6.3 Evidence to recommendations

The GDG discussed the evidence and agreed the evidence statements. The GDG also acknowledged that the evidence is of qualitative nature and the information from the two DIPEx modules was the largest study and hence most representative. The GDG then discussed the applicability of the evidence to each key stage of the general critical care patient's rehabilitation care pathway.

Patient's rehabilitation care pathway

i) During the critical care stay

The GDG discussed the first evidence statement and agreed that three of the five key elements of information and support needs should be recommended during patient's critical care stay, for example, information on critical illness and treatment, equipment used, and the need to deliver such information repeatedly (this is because patients commonly suffer short-term memory problems and often lose consciousness during critical care). Based on the evidence, expert experience and patient representatives' experience, the GDG also agreed that information on critical illness and treatment could be delivered through the use of ICU diaries. The GDG also agreed that if the patient has the capacity to give formal consent, or formal consent is given by the patient's family and/or carer (if the patient lacks capacity to do so), the inclusion of photographs of the patient in the ICU diaries may be helpful for the patient to see how ill they were during recovery. The GDG further discussed the other two key elements: physical problems and recovery; and sharing the information with families/carers. The GDG acknowledged that information on physical problems and recovery is important, however during critical care, early conversations with patients are likely to be dominated by how to survive the critical illness. Detailed information on physical problems and recovery is therefore not appropriate at this stage. Nevertheless, brief

information on possible short-term and/or long-term problems which may require rehabilitation is suitable. Regarding sharing all the information with the family/carer, the patient representatives stressed that during critical care stay, most patients would not have the capacity to give formal consent. They could be still very ill or even unconscious. Therefore sharing information with their families/carers is important at this stage. However, as the patient gets better, for example when the patient has been discharged to ward-based care, consideration needs to be given with regard to patient confidentially. Hence, the GDG concluded, during critical care stay, all information should be shared with the family/carer unless the patient has the capacity to object.

ii) Before discharge from critical care and during ward-based care

The GDG discussed the second evidence statement and all GDG members, including the patient representatives, agreed that all three key elements of information and support needs should be recommended before patients' critical care discharge and during ward-based care. These include information on sleep, hallucination, possible negative emotions with particular emphasis on the readjustment process; reinforced information on possible short-term and/or long-term problems which may require rehabilitation; information on patients' rehabilitation care pathways; information on transfer; and the differences between critical care and ward-based care. The GDG also agreed and wanted to stress the importance of structured handover from critical care to ward-based care. Hence, the GDG suggested that specific recommendations from this guideline should cross refer to recommendations made in the NICE 'Acutely ill patients in hospital: recognition and response to acute illness in adults in hospital' on transfer, structured handover and shared responsibility between different medical teams. In terms of sharing information with the family/carer, as previously discussed, the GDG agreed that patients' confidentiality should be respected and if the patient does not object, information should be shared with the family/carer.

iii) Before discharge to home or community care

The GDG discussed the third evidence statement and all GDG members, including the patient representatives, agreed that all three key elements of

information and support needs should be recommended before the patient is discharged back home or to community care. These include information on physical recovery and goals setting; information on diet and continuing treatments; and information on local statutory and non-statutory support services. In terms of preparing patients to go home, the GDG, especially the patient representatives, stressed that this could be assisted by providing information on how to manage activities of daily living which should include self-care and re-engaging with everyday life. With special input from the patient representatives, the GDG also recognised that advice and information on driving, returning to work or normal activities, housing and benefits are also very important to prepare patients to recover at home. Again, as previously discussed regarding patients' confidentiality, if the patient does not object, detailed information should be shared with the family/carer. Nevertheless, the GDG and the carer representative agreed that general guidance on carers' own needs, and what to expect regarding how to support the patient at home, should be provided to the family/carer.

iv) 2-3 months after discharge from critical care

The GDG discussed the fourth evidence statement and all agreed that all four key elements of information and support needs are important. However, the GDG agreed that the first three key elements of information (which are physical recovery, impact on daily living and non-physical morbidity) should already be covered by recommendation 1.1.7 when the 2-3 month assessment is carried out. Regarding information on statutory and non-statutory supportive services (the fourth key element), the GDG agreed that this should be provided before hospital discharge but not when patients were already back home. Since all these key elements had already been discussed and covered in previous sections, the GDG concluded that there is no need to repeat the recommendations at this stage of the patient's rehabilitation care pathway.

2.6.4 Health economics

What information and support needs are viewed as important by carers of family or adult patients who have developed rehabilitation needs following a period of critical illness?

This was not considered to be a question for which an economic analysis would be relevant.

2.7 Research recommendations

- Which screening tools have the best clinical utility to identify those at risk of physical, psychological and cognitive dysfunction after critical illness and monitor the patients' progress during rehabilitation?
  - Research is required that links the result of identifying those at risk of physical, psychological and cognitive dysfunction after critical illness to outcomes such as health related quality of life, morbidity and survival. Quality of life should be assessed using generic measures such as the EQ-5D to enable economic evaluation on the cost effectiveness of these screening tools.
- What are the clinical effectiveness and cost-effectiveness of early (within ICU) versus late (post ICU) physical rehabilitation strategies on physical morbidity, patient experience, quality of life (assessed using generic measures such as the EQ-5D) and critical care/hospital length of stay?
- What are the clinical effectiveness and cost-effectiveness of physical rehabilitation strategies and psychological rehabilitation strategies for higher risk patients that start in, or soon after, critical illness and continue over the first year after critical illness?
- When is the optimal time for screening and assessing critical care adult patients at risk of physical and non-physical morbidity associated with their treatment experience and critical illness?
- When is the optimal time for initiating rehabilitation for critical care adult patients who have developed physical and non-physical morbidity associated with their treatment experience and critical illness?

- What is the natural history, new therapeutic options and response to treatment for psychological conditions that are associated with critical illness such as anxiety, depression and PTSD?

3 References, glossary and abbreviations

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3.2 Glossary and abbreviations

3.2.1 Glossary

Absolute risk reduction (Risk difference)

The difference in event rates between two groups (one subtracted from the other) in a comparative study.

Before-and-after study

A study design that involves intervention and control groups other than by random process, and inclusion of baseline period of assessment of main outcomes. There are two minimum criteria for this study design which are: (i) pre- and post-intervention periods for study and control sites are the same, and (ii) studies using second site as controls and the control sites are comparable with respect to dominant reimbursement system, level of care, setting of care and academic status.

Bias

Systematic (as opposed to random) deviation of the results of a study from the 'true' results that is caused by the way the study is designed or conducted.

Carer (caregiver)

Someone other than a health professional who is involved in caring for a person with a medical condition.

Case control study

Comparative observational study in which the investigator selects individuals who have experienced an event (for example, developed a disease) and others who have not (controls), and then collects data to determine previous exposure to a possible cause.

Clinical effectiveness

The extent to which an intervention produces an overall health benefit in routine clinical practice.

Clinical/test utility

Clinical/test utility in its narrowest sense refers to the ability of a screening or diagnostic test to prevent or ameliorate adverse health outcomes such as mortality, morbidity, or disability through the adoption of efficacious treatments conditioned on test results. A screening or diagnostic test alone does not have inherent utility; because it is the adoption of therapeutic or preventive

interventions that influences health outcomes, the clinical utility of a test depends on effective access to appropriate interventions.

Cohort study

(also known as follow-up, incidence, longitudinal, or prospective study): An observational study in which a defined group of people (the cohort) is followed over time. Outcomes are compared in subsets of the cohort who were exposed or not exposed (or exposed at different levels) to an intervention or other factor of interest.

Comorbidity

Two or more diseases or conditions occurring at the same time, such as depression and anxiety.

Confidence interval

The range within which the ‘true‘ values (for example, size of effect of an intervention) are expected to lie with a given degree of certainty (for example, 95% or 99%). (Note: confidence intervals represent the probability of random errors, but not systematic errors or bias).

Concurrent validity

Concurrent validity is demonstrated where a test correlates well with a measure that has previously been validated. The two measures may be for the same construct, or for different, but presumably related, constructs.

Consensus methods

Techniques that aim to reach an agreement on a particular issue. Formal consensus methods include Delphi and nominal group techniques, and consensus development conferences. In the development of clinical guidelines, consensus methods may be used where there is a lack of strong research evidence on a particular topic. Expert consensus methods will aim to reach agreement between experts in a particular field.

Cost-effectiveness analysis

An economic evaluation that compares alternative options for a specific patient group looking at a single effectiveness dimension measured in a non-monetary (natural) unit. It expresses the result in the form of an incremental (or average or marginal) cost-effectiveness ratio.

Criterion validity

Criterion or concrete validity is the extent to which the measures are demonstrably related to concrete criteria in the "real" world. This type of validity is often divided into "concurrent" and "predictive" subtypes. The term "concurrent validity" is reserved for demonstrations relating a measure to other concrete criteria assessed simultaneously. "Predictive validity" refers to the degree to which any measure can predict future concrete events. These variables are often represented as “intermediate” and “ultimate” criteria.

Critical care

Critical care is now used as a term that encompasses “intensive care” or “intensive therapy”; units providing such care are referred to as intensive care (ICU) or intensive therapy (ITU) units respectively and synonymously, and what used to be called “high dependency” care provided in “HDU”s.

Cronbach’s alpha

Cronbach's alpha will generally increase when the correlations between the items in a test increase. For this reason the coefficient is also called the internal consistency or the *internal consistency reliability* of the test.

DSM-IV diagnostic criteria

DSM-IV is published by the American Psychiatric Association and provides diagnostic criteria for mental disorders. It is used in the United States, United Kingdom and in varying degrees around the world, by clinicians, researchers, psychiatric drug regulation agencies, health insurance companies, pharmaceutical companies and policy makers.

Economic evaluation

Technique developed to assess both costs and consequences of alternative health strategies and to provide a decision making framework.

Guideline Development Group

A group of healthcare professionals, patients, carers and members of the Short Clinical Guidelines Technical Team who develop the recommendations for a clinical guideline. The group writes draft guidance, and then revises it after a consultation with organisations registered as stakeholders.

Generalisability

The degree to which the results of a study or systematic review can be extrapolated to other circumstances, particularly routine healthcare situations in the NHS in England and Wales.

Heterogeneity

A term used to illustrate the variability or differences between studies in the estimates of effects.

Internal reliability

Used to assess the consistency of results across items within a test.

Inter-rater reliability

Used to assess the degree to which different raters/observers give consistent estimates of the same phenomenon.

Kappa

Kappa coefficient is a statistical measure of inter-rater reliability. It is generally thought to be a more robust measure than simple percent agreement calculation because kappa takes into account the agreement occurring by chance.

Narrative summary

Summary of findings given as a written description.

Negative predictive value

The proportion of patients with negative test results who are correctly diagnosed.

Odds ratio

A measure of treatment effectiveness. The odds of an event happening in the intervention group, divided by the odds of it happening in the control group. The 'odds' is the ratio of non-events to events.

Phenomenological approach

Phenomenology is one of many types of qualitative research that examines the lived experiences of humans. Phenomenological researchers hope to gain understanding of the essential 'truths' (that is, essences) of a phenomenon as experienced by people.

Physical morbidity

Including muscle loss, muscle weakness, joint pain, loss of bone, sensory problems, swallowing and communication problems.

Non-physical morbidity

Including anxiety, depression, post-traumatic stress disorder, post-traumatic stress symptoms and cognitive dysfunction.

Positive predictive value

The proportion of people with a positive test result who actually have the disease.

Purposive sampling

A purposive sample is one which is selected by the researcher subjectively. The researcher attempts to obtain a sample that appears to him/her to be representative of the population and will usually try to ensure that a range from one extreme to the other is included.

QUADAS

The Quality Assessment of Diagnostic Accuracy Studies (QUADAS) tool. A tool for the quality assessment of studies of the accuracy of diagnostic technologies.

Qualitative research

Research concerned with subjective outcomes relating to social, emotional and experiential phenomena in health and social care.

Quality-adjusted life year (QALY)

A statistical measure, representing 1 year of life, with full quality of life.

Randomised controlled trial

A form of clinical trial to assess the effectiveness of medicines or procedures. Considered reliable because it tends not to be biased.

Relative risk

Also known as risk ratio; the ratio of risk in the intervention group to the risk in the control group. The risk (proportion, probability or rate) is the ratio of people with an event in a group to the total in the group. A relative risk (RR) of 1 indicates no difference between comparison groups. For undesirable outcomes, an RR that is less than 1 indicates that the intervention was effective in reducing the risk of that outcome.

ROC analysis

A receiver operating characteristic (ROC), or simply ROC curve, is a graphical plot of the sensitivity vs. (1 - specificity) for a binary classifier system as its discrimination threshold is varied. ROC analysis provides tools to select possibly optimal models and to discard suboptimal ones independently from (and prior to specifying) the cost context or the class distribution. ROC analysis is related in a direct and natural way to cost/benefit analysis of diagnostic decision making.

Sensitivity (of a test)

The proportion of people classified as positive by the gold standard who are correctly identified by the study test.

Specificity (of a test)

The proportion of people classified as negative by the gold standard who are correctly identified by the study test.

Systematic review

Research that summarises the evidence on a clearly formulated question according to a pre-defined protocol using systematic and explicit methods to identify, select and appraise relevant studies, and to extract, collate and report their findings. It may or may not use statistical meta-analysis.

Tracheostomy

Tracheotomy and tracheostomy are surgical procedures on the neck to open a direct airway through an incision in the trachea (the windpipe).

3.2.2 Abbreviations

CI	Confidence interval
GRADE	Grading of Recommendations Assessment, Development and Evaluation
ICU	Intensive care unit
NPV	Negative predictive value
NS	Not significant
OR	Odds ratio
PPV	Positive predictive value
QALY	Quality-adjusted life year
QUADAS	Quality Assessment of Studies of Diagnostic Accuracy included in Systematic Reviews
RCT	Randomised controlled trial
RR	Relative risk
SD	Standard deviation

4 Methods

4.1 Aim and scope of the guideline

4.1.1 Scope

NICE guidelines are developed in accordance with a scope that defines what the guideline will and will not cover (see appendix 1). The scope of this guideline is available from http://www.nice.org.uk/guidance/index.jsp?action=download&o=41274

The aim of this guideline is to provide evidence-based recommendations to guide healthcare professionals in the appropriate care of adults requiring rehabilitation after a period of critical illness.

4.2 Development methods

This section sets out in detail the methods used to generate the recommendations for clinical practice that are presented in the previous chapters of this guideline. The methods used to develop the recommendations are in accordance with those set out by the National Institute for Health and Clinical Excellence ('NICE' or 'the Institute') in 'The guidelines manual' (2007) (available at: www.nice.org.uk/guidelinesmanual).

4.2.1 Developing the guideline scope

The draft scope, which defined the areas the guideline would and would not cover, was prepared by the Short Clinical Guidelines Technical Team on the basis of the remit from the Department of Health, consultation with relevant experts and a preliminary search of the literature to identify existing clinical practice guidelines, key systematic reviews and other relevant publications. The literature search gave an overview of the issues likely to be covered by the guideline and helped define key areas. It also informed the Short Clinical Guidelines Technical Team of the volume of literature likely to be available in the topic area, and therefore the amount of work required.

The draft scope was tightly focused and covered three clinical topic areas.

The draft scope was the subject of public consultation.

4.2.2 Forming and running the Short Clinical Guideline Development Group

The short clinical guideline on Rehabilitation after critical care was developed by a Guideline Development Group consisting of 15 members, one co-opted expert who attended one morning of the second Guideline Development Group meeting, and the Short Clinical Guidelines Technical Team. The Guideline Development Group had a chair, healthcare professional members and patient/carer members who were recruited through open advertisement. Development took 4 months and the Guideline Development Group met on three occasions, every 6 weeks.

4.2.3 Developing structured clinical questions

The third step in the development of the guidance was to refine the scope into a series of structured clinical questions. The structured clinical questions formed the starting point for the subsequent evidence reviews and facilitated the development of recommendations by the Guideline Development Group.

The structured clinical questions were developed by the Guideline Development Group with assistance from the Short Clinical Guidelines Technical Team. As necessary, the questions were refined into specific review questions by the project teams to aid literature searching, appraisal and synthesis. The full list of structured clinical questions and review questions are shown in appendix 2.

The Guideline Development Group and Short Clinical Guidelines Technical Team agreed appropriate review protocols for each review question. All review protocols for the review questions are shown in appendix 4.

4.2.4 Developing recommendations

For each review question, recommendations were derived from the evidence summaries or GRADE profiles and evidence statements presented to the Guideline Development Group.

4.2.5 Literature search

The evidence reviews used to develop the guideline recommendations were underpinned by systematic literature searches, following the methods described in 'The guidelines manual 2007'. The purpose of systematically searching the literature is to attempt to comprehensively identify the published evidence to answer the key clinical questions developed by the Guideline Development Group and Short Clinical Guidelines Technical Team.

The search strategies for the key clinical questions were developed by the Information Services Team with advice from the Short Clinical Guidelines Technical Team. Structured clinical questions were developed using the PICO (population, intervention, comparison, outcome) model, and were translated into search strategies using subject heading and free text terms. The strategies were run across a number of databases with no date restrictions imposed on the searches. When required, filters to identify systematic reviews, randomised controlled trials and observational studies were appended to the search strategies to retrieve high quality evidence.

To identify economic evaluations the NHS Economic Evaluation Database (NHS EED) and the Health Economic Evaluations Database (HEED) were searched. Search filters to identify economic evaluations and quality of life studies were used to interrogate bibliographic databases. There were no date restrictions imposed on the searches.

In addition to the systematic literature searches, the Guideline Development Group was asked to alert the Short Clinical Guidelines Technical Team to any additional evidence, published, unpublished or in press, that met the inclusion criteria.

The searches were undertaken between June 2008 and September 2008. Full details of the systematic search, including the sources searched and the MEDLINE strategies for each evidence review, are presented in appendix 3.

4.2.6 Reviewing the evidence

The aim of the literature review was to systematically identify and synthesise relevant evidence in order to answer the specific key clinical questions developed from the guideline scope. The guideline recommendations were evidence based if possible; if evidence was not available, informal consensus of opinion within the Guideline Development Group was used. The need for future research was also specified. This process required four main tasks: selection of relevant studies; assessment of study quality; synthesis of the results; and grading of the evidence. The Technical Analyst had primary responsibility for reviewing the evidence but was supported by the Project Lead, Information Scientist and Health Economist.

After the scope was finalised, searches based on individual key clinical questions were undertaken. The searches were first sifted by the Short Clinical Guidelines Technical Team using title and abstract to exclude papers that did not address the specified key clinical question. After selection based on title and abstract, the full text of the papers were obtained and reviewed by the Short Clinical Guidelines Technical Team in order to determine which studies should be included in the literature review. Studies suggested or submitted by the Guideline Development Group and expert advisers were also reviewed for relevance to the key clinical questions and included if they met the inclusion criteria.

The papers chosen for inclusion were then critically appraised by the Short Clinical Guidelines Technical Team for their methodological rigour against a number of criteria that determine the validity of the results. These criteria differed according to study type and were based on the checklists included in 'The guidelines manual 2007' by NICE (available from www.nice.org.uk/guidelinesmanual). The checklists that were used in this particular guideline (see appendix 6).

The data were extracted to standard evidence table templates. The findings were summarised by the Short Clinical Guidelines Technical Team into both a series of evidence statements and an accompanying narrative summary.

4.2.7 Grading the evidence

Intervention studies

Studies that meet the minimum quality criteria were ascribed a level of evidence to help the guideline developers and the eventual users of the guideline understand the type of evidence on which the recommendations have been based.

There are many different methods of assigning levels to the evidence and there has been considerable debate about what system is best. A number of initiatives are currently underway to find an international consensus on the subject. NICE has previously published guidelines using different systems and is now examining a number of systems in collaboration with the NCCs and academic groups throughout the world to identify the most appropriate system for future use.

Until a decision is reached on the most appropriate system for the NICE guidelines, the Short Clinical Guidelines Technical Team will use the checklists currently proposed in The Guidelines Manual (2008) from NICE. For the checklists please see appendix 6.

Presenting intervention studies with modified GRADE

The reader of a guideline should be able to follow a clear path from the question posed, through the summary of the evidence collected to address the question (linking to detailed evidence tables if desired), to the consideration of the evidence and the formulation of appropriate recommendations.

Grading or Recommendations Assessment, Development and Evaluation (GRADE) is a system for grading the quality of evidence that can be applied across a wide range of interventions and contexts. The system is a useful way to summarise evidence of effectiveness by the outcomes for which data have been collected. This approach uses an ‘evidence profile’ that combines presentation of quality assessment and outcome data. This is then followed by a short evidence statement summarising what the evidence has shown.

In the modified GRADE system, the quality of evidence indicates the extent to which one can be confident that an estimate of effect is correct. The steps in

this approach, which follow these judgements, are to make sequential judgements about:

- the quality of evidence across studies for each important outcome
- which outcomes are critical to a decision
- the overall quality of evidence across these critical outcomes
- the balance between benefits and harms
- the strength of recommendations.

A systematic and explicit approach to making judgements about the quality of evidence and the strength of recommendations can help to prevent errors, facilitate critical appraisal of these judgements, and improve communication of this information. More information about GRADE and its utilisation is available from www.grade.workinggroup.org

Diagnostic studies

Studies that are reviewed for questions about diagnosis or test utility were addressed using the newly developed pilot checklist for diagnostic studies - the Quality Assessment of Studies of Diagnostic Accuracy (QUADAS) (see appendix 6). The most appropriate study design to answer a question relating to diagnostic accuracy or test utility is a cross-sectional study. Case–control studies can also be used but this type of design is more prone to bias, and often results in inflated estimates of diagnostic test accuracy.

The current lack of empirical evidence about the size and direction of bias contributed by specific aspects of the design and conduct of studies on diagnostic test accuracy or test utility means that making judgements about the overall quality of studies can be difficult. Before starting the review, an assessment should be made about which quality appraisal criteria (from the QUADAS checklist) are likely to be the most important indicators of quality for the particular diagnostic test accuracy or test utility question being addressed. These criteria will be useful to guide decisions about the overall quality of individual studies. Clinical input (for example, from a GDG member) may be needed to identify the most appropriate quality criteria.

Qualitative studies

Studies about patient experience are likely to be qualitative studies or cross-sectional surveys. Qualitative studies in this guideline were assessed using the checklist for qualitative studies (see appendix 6). There is uncertainty about the usefulness of checklists for the quality appraisal of qualitative research and about which appraisal criteria are the most important for assessing overall study quality. It is therefore appropriate to consider, before starting the review, which quality appraisal criteria (from the checklist in appendix 6) are likely to be the most important indicators of quality for the specific research question being addressed. These criteria may be helpful in guiding decisions about the overall quality of individual studies, and when summarising and presenting the body of evidence for the research question about patient experience as a whole. There is no checklist for the quality appraisal of cross-sectional surveys, but such surveys should be assessed for their relevance to the population under consideration and for the existence of significant bias (for example, non-response bias).

4.2.8 Evidence to recommendations

The evidence tables and narrative summaries for the key clinical questions being discussed were made available to the Guideline Development Group 1 week before the scheduled Guideline Development Group meeting.

All Guideline Development Group members were expected to have read the evidence tables and narrative summaries before attending each meeting. The review of the evidence had three components. First, the Guideline Development Group discussed the evidence tables and narrative summaries and corrected any factual errors or incorrect interpretation of the evidence. Second, evidence statements, which had been drafted by the Short Clinical Guidelines Technical Team, were presented to the Guideline Development Group and the Guideline Development Group agreed the correct wording of these. Third, from a discussion of the evidence statements and the experience of Guideline Development Group members recommendations were drafted. The Short Clinical Guidelines Technical Team explicitly flagged up with the Guideline Development Group that it should consider the following criteria

(considered judgement) when developing the guideline recommendations from the evidence presented:

- internal validity
- consistency
- generalisability (external validity)
- clinical impact
- cost effectiveness
- ease of implementation
- patient's perspective
- social value judgement
- overall synthesis of evidence.

The Guideline Development Group was able to agree recommendations through informal consensus. The process by which the evidence statements informed the recommendations is summarised in an 'evidence to recommendations' section in the relevant evidence review. Each recommendation was linked to an evidence statement if possible. If there was a lack of evidence of effectiveness, but the Guideline Development Group was of the view that a recommendation was important based on the Guideline Development Group members' own experience, this was noted in the 'evidence to recommendations' section.

4.2.9 Health economics

An economic evaluation aims to integrate data on the benefits (ideally in terms of quality-adjusted life years [QALYs]), harms and costs of alternative options. An economic appraisal will consider not only whether a particular course of action is clinically effective, but also whether it is cost-effective (that is, value for money). If a particular treatment strategy were found to yield little health gain relative to the resources used, then it could be advantageous to redirect resources to other activities that yield greater health gain.

To assess the cost effectiveness of strategies for the rehabilitation of patients in intensive care a systematic review of the literature was conducted. In addition the Guideline Development Group was questioned over any

potentially relevant unpublished data. The search of the literature identified no relevant economic studies. The majority of studies identified were concerned with costing of intensive care or health related quality of life or survival following a stay in intensive care. None of these studies compared a rehabilitation intervention with standard care.

Due to insufficient clinical evidence a cost effectiveness analysis was not possible.

Health economics statements are made in the guideline in sections in which the use of NHS resources is considered.

4.2.10 Consultation

To be added after consultation

4.2.11 Other national guidance

NICE has issued the following related guidance:

Anxiety: management of anxiety (panic disorder, with or without agoraphobia, and generalised anxiety disorder) in adults in primary, secondary and community care. NICE clinical guideline CG22 (2004)

Depression: management of depression in primary and secondary care. NICE clinical guideline CG23 (2004)

Dementia: Supporting people with dementia and their carers in health and social care. NICE clinical guideline CG42 (2006)

Head injury: triage, assessment, investigation and early management of head injury in infants, children and adults. NICE clinical guideline CG56 (2007)

MI: secondary prevention: secondary prevention in primary and secondary care for patients following a myocardial infarction. NICE clinical guideline CG48 (2007)

Nutrition support in adults: oral nutrition support, enteral tube feeding and parenteral nutrition. NICE clinical guideline CG32 (2006)

Anxiety: Management of post-traumatic stress disorder in adults in primary, secondary and community care. NICE clinical guideline CG26 (2005)

Stroke: The diagnosis and acute management of stroke and transient ischaemic attacks. NICE clinical guideline (to be published in July 2008)

Delirium: diagnosis, prevention and management of delirium. NICE clinical guideline (to be published in April 2010).

4.2.12 Piloting and implementation

It is beyond the scope of the work to pilot the contents of this guideline or validate any approach to implementation. These limitations excepted, every effort has been made to maximise the relevance of recommendations to the intended audience through the use of a guideline development group with relevant professional and patient involvement, by use of relevant experienced expert reviewers and the stakeholder process facilitated by the NICE Short Clinical Guidelines Technical Team. Implementation support tools for this guideline will be available from the Implementation Team at NICE.

4.2.13 Audit methods

The guideline recommendations have been used to develop clinical audit support for monitoring local practice. This is an essential implementation tool for monitoring the uptake and impact of guidelines, and thus needs to be clear and straightforward for organisations and professionals to use.

NICE develops audit support for all its guidance programmes as part of its implementation strategy.

4.2.14 Scheduled review of this guideline

The guidance has been developed in accordance with the NICE guideline development process for short clinical guidelines. This has included allowing registered stakeholders the opportunity to comment on the draft guidance. In additional the first draft was reviewed by an independent Guideline Review Panel established by NICE.

The comments made by stakeholders, peer reviewers and the Guideline Review Panel were collated and presented anonymously for consideration by the Guideline Development Group. All comments were considered systematically by the Guideline Development Group and the Project Team recorded the agreed responses.

This guideline will be considered for an update following the current process (chapter 15 of 'The guidelines manual') . However, if the evidence available has not changed we will not update it. Any agreed update would be carried out by the Short Clinical Guidelines Technical Team in conjunction with the Guideline Development Group. Alternatively the topic may be referred to the NICE Topic Selection Panel for it to consider developing a standard clinical guideline.

5 Contributors

5.1 The Guideline Development Group

The Guideline Development Group was composed of relevant healthcare professionals, patient representatives and NICE technical staff.

The members of the Guideline Development Group are listed below.

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The following person was not a full member of the Guideline Development Group but was co-opted onto the group as an expert adviser:

Nicholas Hart
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5.1.1 The Short Clinical Guidelines Technical Team

The Short Clinical Guidelines Technical Team was responsible for this guideline throughout its development. It was responsible for preparing information for the Guideline Development Group, for drafting the guideline and for responding to consultation comments. The following people, who are employees of NICE, made up the technical team working on this guideline.

Dr Tim Stokes –	Guideline Lead and Associate Director
Toni Tan –	Technical Analyst
Ruth McAllister -	Health Economist
Kathryn Chamberlain -	Project Manager
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Nicole Elliott - Commissioning Manager

Emma Banks - Coordinator

5.1.2 Guideline Review Panel

[To be inserted into final guideline]

5.1.3 List of stakeholders

[To be inserted into final guideline]

5.2 Declarations

5.2.1 Authorship and citation

Authorship of this full guideline document is attributed to the NICE Short Clinical Guidelines Technical Team and members of the Guideline Development Group under group authorship.

The guideline should be cited as: [to be inserted].

5.2.2 Declarations of interest

A full list of all declarations of interest made by this Guideline Development Group is available on the NICE website (www.nice.org.uk).