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Rehabilitation after critical illness

NICE clinical guideline 83
Developed by the Centre for Clinical Practice at NICE

NICE clinical guideline 83
Rehabilitation after critical illness

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- The full guideline – all the recommendations, details of how they were developed, and reviews of the evidence they were based on.

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Rehabilitation after critical illness

Full guideline

January 2009

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.

Update information

July 2018: Cross-references to other NICE guidelines were added.

Contents

Disclaimer

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Foreword

Approximately 110,000 people (estimated from the UK Intensive Care National Audit and Research Centre [ICNARC] Case Mix Programme [CMP] Summary Statistics) spend time in critical care units in England and Wales each year, the majority surviving 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 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 critical care, and who thus understood the context of the patients' clinical stories. Research on the longer-term consequences of critical illness has shown that significant numbers of patients surviving critical illness have important continuing problems. For many, discharge from critical care is the start of an uncertain journey to recovery characterised by, among other problems, weakness, loss of energy and physical difficulties, anxiety, depression, post-traumatic stress (PTS) phenomena and, for some, a loss of mental faculty (termed cognitive function). Family members become informal caregivers, and this itself can exert a secondary toll of ill-health; family relationships can become altered and financial security imperilled. Recovery from illness is highly individual, and few studies have been able to demonstrate a close relationship between features of the acute illness and longer-term impact. Logically, patients who have had prolonged episodes of critical illness are likely to have greater long-term difficulties, however patients with relatively short intensive care stays may also need substantial help.

Thus the *optimisation* of recovery as a therapeutic objective, rather than mere survival, has developed increasing prominence. Identified as an important area during the creation of 'Acutely ill patients in hospital' (NICE clinical guideline 50), the Department of Health charged NICE 'To develop a short clinical guideline on rehabilitation after a period of critical illness requiring a stay in an 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; provided in intensive care units (ICUs) or intensive therapy units (ITUs), together with what used to be called high-dependency care provided in high-dependency units (HDUs). Intensive care, or level 3 care, generally involves the support of one or more failing organ system, usually including the lungs, whereas high dependency care, or level 2 care, supports one system. Recently the distinctions have become blurred, hence the increasing use of the term *critical* care.

For simplicity, 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 (PTSD), and cognitive dysfunction.

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

The Guideline Development Group (GDG) also recognised the strain suffered by many families, and the commitment involved in helping the recovering patient. There is a tension between providing information to help families cope, and recognising that many patients may not wish specific information to be shared; 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.

For many patients the recovery after critical illness is relatively straightforward and it is important not to lose sight of this. What is clear is that tens of thousands of

patients leave critical care to go home each year, and it is likely that poor-quality recovery 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, which are detailed later in the document. Additionally, of particular strategic importance is the lack of detailed understanding of the pathophysiology of the muscle wasting that is a feature of critical illness, and this area needs to be addressed. Critical illness polyneuropathy and myopathy are related and important problems. Alongside this, a better understanding of the impact of critical illness on the brain, and its relationship to sedation, neuroinflammation, delirium and future cognitive impairment is a priority. There is scope here for interventional trials in the near future. A thorough understanding of the socioeconomic consequences of critical illness at both individual and society levels is also needed to inform broader policy. As the majority of the recommendations in this guideline are consensus based, this guideline should stimulate, rather than stifle, research, and the impact of the introduction of the recommendations, along with alternative approaches, should be thoroughly evaluated.

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, that can be implemented in the NHS for the benefit of patients. The GDG and the technical team have worked extremely hard picking their way through a difficult and somewhat patchy evidence base; 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 hope that when this guideline is reviewed, the evidence base for specific interventions and service delivery models is more substantial.

Stephen Brett
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Imperial College Healthcare NHS Trust
Guideline Development Group Chair

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 inpatient 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 and in line with the Mental Capacity Act (2005), 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

The Guideline Development Group (GDG) used the following definitions in this guideline.

- Short clinical assessment: a brief clinical assessment to identify patients who may be at risk of developing physical and non-physical morbidity.
- Comprehensive clinical assessment: a more detailed assessment to determine the rehabilitation needs of patients who have been identified as being at risk of developing physical and non-physical morbidity.
- Functional assessment: an assessment to examine the patient's daily functional ability.
- Short-term rehabilitation goals: goals for the patient to reach before they are discharged from hospital.
- Medium-term rehabilitation goals: goals to help the patient return to their normal activities of daily living after they are discharged from hospital.
- Physical morbidity: problems such as muscle loss, muscle weakness, musculoskeletal problems including contractures, respiratory problems, sensory problems, pain, and swallowing and communication problems.
- Non-physical morbidity: psychological, emotional and psychiatric problems, and cognitive dysfunction.
- Multidisciplinary team: a team of healthcare 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.

1.1 List of all recommendations

Key principle of care

To ensure continuity of care, healthcare professional(s) with the appropriate competencies[1] should coordinate the patient's rehabilitation care pathway. Key elements of the coordination are as follows.

- Ensure the short-term and medium-term rehabilitation goals are reviewed, agreed and updated throughout the patient's rehabilitation care pathway.
- Ensure the delivery of the structured and supported self-directed rehabilitation manual, when applicable.
- Liaise with primary/community care for the functional reassessment at 2–3 months after the patient's discharge from critical care.
- Ensure information, including documentation, is communicated between hospitals and to other hospital-based or community rehabilitation services and primary care services.
- Give patients the contact details of the healthcare professional(s) on discharge from critical care, and again on discharge from hospital.

See the NICE guideline on patient experience in adult NHS services.

During the critical care stay

During the patient's critical care stay and as early as clinically possible, perform a short clinical assessment to determine the patient's risk of developing physical and non-physical morbidity (see table 1).

For patients at risk of physical and non-physical morbidity, perform a comprehensive clinical assessment to identify their current rehabilitation needs. This should include assessments by healthcare professionals experienced in critical care and rehabilitation.

[1] 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).

For patients at risk, agree short-term and medium-term rehabilitation goals, based on the comprehensive clinical assessment. The patient's family and/or carer should also be involved[2].

The comprehensive clinical assessment and the rehabilitation goals should be collated and documented in the patient's clinical records.

For patients at risk, start rehabilitation as early as clinically possible, based on the comprehensive clinical assessment and the rehabilitation goals. Rehabilitation should include:

- measures to prevent avoidable physical and non-physical morbidity, including a review of previous and current medication
- nutrition support, based on the recommendations in 'Nutrition support in adults' (NICE clinical guideline 32)
- an individualised, structured rehabilitation programme with frequent follow-up reviews. The details of the structured rehabilitation programme and the reviews should be collated and documented in the patient's clinical records.

Give patients the following information during their critical care stay. Also give the information to their family and/or carer[3], unless the patient disagrees.

- Information about the patient's critical illness, interventions and treatments.
- Information about the equipment used during the patient's critical care stay.
- If applicable, information about any possible short-term and/or long-term physical and non-physical problems which may require rehabilitation.

Deliver all the above information more than once during the patient's critical care stay.

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

Before discharge from critical care

For patients who were previously identified as being at low risk, perform a short clinical assessment before their discharge from critical care to determine their risk of developing physical and non-physical morbidity (see table 1).

For patients at risk, and patients who started the individualised, structured rehabilitation programme in critical care, perform a comprehensive clinical reassessment to identify their current rehabilitation needs. The comprehensive reassessment should pay particular attention to:

- physical, sensory and communication problems (see table 2)
- underlying factors, such as pre-existing psychological or psychiatric distress
- symptoms that have developed during the critical care stay, such as delusions, intrusive memories, anxiety, panic episodes, nightmares, flashback episodes or depression (see the NICE guideline on the prevention, diagnosis and management of delirium).

For patients who were previously identified as being at risk during critical care, the outcomes of the comprehensive reassessment should inform the individualised, structured rehabilitation programme (recommendation 1.1.6).

For patients at risk, agree or review and update the rehabilitation goals, based on the comprehensive reassessment. The family and/or carer should also be involved, unless the patient disagrees.

Ensure that the transfer of patients and the formal structured 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.

Give patients the following information before, or as soon as possible after, their discharge from critical care. Also give the information to their family and/or carer, unless the patient disagrees.

- 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, and staffing and monitoring levels.
- Information about the transfer of clinical responsibility to a different medical team (this includes information about the formal structured handover of care recommended in 'Acutely ill patients in hospital' (NICE clinical guideline 50).
- If applicable, emphasise the information about possible short-term and/or long-term physical and non-physical problems that may require rehabilitation.
- If applicable, information about sleeping problems, nightmares and hallucinations and the readjustment to ward-based care.

During ward-based care

For patients who were previously identified as being at low risk before discharge from critical care, perform a short clinical assessment to determine their risk of physical and non-physical morbidity (see table 1).

For patients at risk, perform a comprehensive clinical reassessment (see recommendation 1.1.9) to identify their current rehabilitation needs.

For patients at risk, offer an individualised, structured rehabilitation programme, based on the comprehensive clinical reassessment[4] and the agreed or updated rehabilitation goals set before the patient was discharged from critical care.

The individualised, structured rehabilitation programme should be developed and delivered by members of a multidisciplinary team, and should include appropriate referrals, if applicable.

Based on clinical judgement and the individual patient's rehabilitation needs, consider offering a structured and supported self-directed rehabilitation

[4] Comprehensive reassessments apply to both those before discharge from critical care and during ward-based care.

manual[5] for at least 6 weeks after discharge from critical care, as part of the individualised, structured rehabilitation programme.

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

Before discharging patients who were receiving the individualised structured rehabilitation programme during ward-based care (recommendation 1.1.15) (see the NICE guideline on the transition between inpatient hospital settings and community or care home settings for adults with social care needs):

- perform a functional assessment which should include the following (also see table 2 for possible examples):

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

  Non-physical dimensions
  - anxiety
  - depression
  - post-traumatic stress-related symptoms
  - behavioural and cognitive problems
  - psychosocial problems.
- assess the impact of the outcomes from the functional assessment on the patient's activities of daily living and participation

[5] The structured and supported self-directed rehabilitation manual (based on Jones et al. 2003) should be coordinated by an appropriately skilled healthcare professional throughout its duration. The optimal time for starting the structured and supported self-directed rehabilitation manual should be based on individual patients' physical and cognitive capacity at different stages of their illness and recovery.

- based on the functional assessment, review, update and agree the rehabilitation goals with the patient. The family and/or carer should be involved if the patient agrees.

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

- discharge arrangements, including appropriate referrals for the necessary ongoing care, are in place 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 and/or carer as appropriate, is aware of the discharge arrangements and understands them (see the NICE guideline on intermediate care including reablement).

Give patients the following information before their discharge to home or community care. Also give the information to their family and/or carer, if the patient agrees.

- Information about their physical recovery, based on the goals set during ward-based care if applicable.
- If applicable, information about diet and any other continuing treatments.
- Information about how to manage activities of daily living including self-care and re-engaging with everyday life.
- If applicable, information about driving, returning to work, housing and benefits.
- Information about local statutory and non-statutory support services, such as support groups.
- General guidance, especially for the family and/or 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.
- Give the patient their own copy of the critical care discharge summary.

2–3 months after discharge from critical care

Review patients with rehabilitation needs 2–3 months after their discharge from critical care. Carry out a functional reassessment of their health and social care needs, using the dimensions in recommendation 1.1.20. If appropriate, also enquire about sexual dysfunction.

The functional reassessment should be face to face in the community or in hospital, performed by an appropriately-skilled healthcare professional(s) who is familiar with the patient's critical care problems and rehabilitation care pathway.

Based on the functional reassessment.

- 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 their rehabilitation goals, or
  - the patient has developed unanticipated physical and/or non-physical morbidity that was not previously identified.
- Give support if the patient is not recovering as quickly as they anticipated.
- If anxiety or depression is suspected, follow the stepped care models recommended in 'Anxiety' (NICE clinical guideline 22) and 'Depression' (NICE clinical guideline 23).
- If PTSD is suspected or the patient has significant symptoms of PTS, refer to 'Post-traumatic stress disorder (PTSD)' (NICE clinical guideline 26).

Table 1 Examples from the short clinical assessment that may indicate the patient is at risk of developing physical and non-physical morbidity

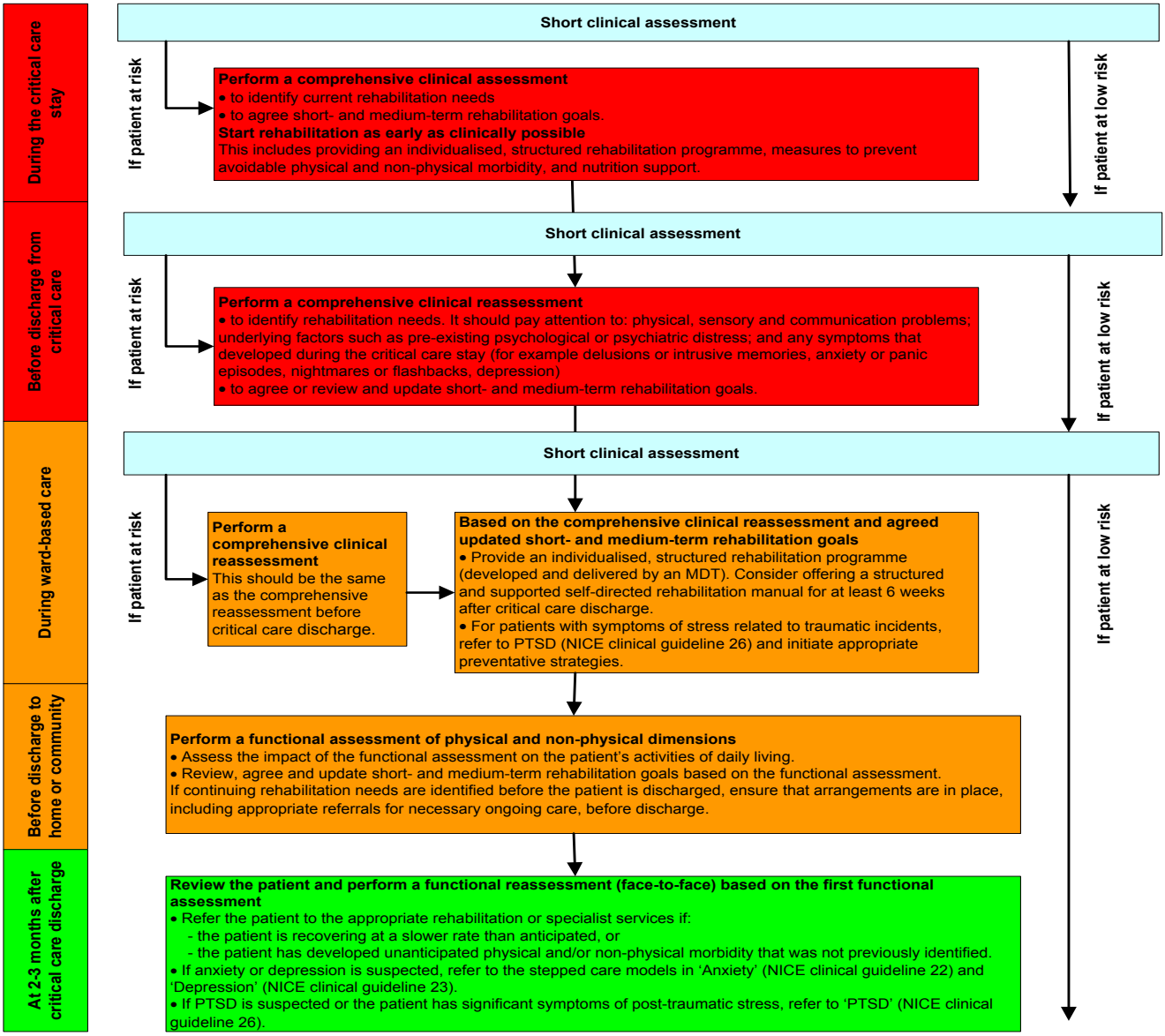
Physical	Unable to get out of bed independently. Anticipated long duration of critical care stay. Obvious significant physical or neurological injury. Lack of cognitive functioning to continue exercise independently. Unable to self ventilate on 35% of oxygen or less. Presence of premorbid respiratory or mobility problems. Unable to mobilise independently over short distances.
Non-physical	Recurrent nightmares, particularly where patients report trying to stay awake to avoid nightmares. Intrusive memories of traumatic events which have occurred prior to admission (for example, road traffic accidents) or during their critical care stay (for example, delusion experiences or flashbacks). New and recurrent anxiety or panic attacks. Expressing the wish not to talk about their illness or changing the subject quickly off the topic.

Note: this list is not exhaustive and healthcare professionals should use their clinical judgement.

Table 2 Symptoms from the functional assessment that may indicate the presence of physical and non-physical morbidity

Physical dimensions	
Physical problems	Weakness, inability/partial ability to sit, rise to standing, or to walk, fatigue, pain, breathlessness, swallowing difficulties, incontinence, inability/partial ability 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, housing, benefits, employment and leisure needs.
Non-physical dimensions	
Anxiety, depression and PTS-related symptoms	New or recurrent somatic symptoms including palpitations, irritability and sweating; symptoms of derealisation and depersonalisation; avoidance behaviour; depressive symptoms including tearfulness and withdrawal; nightmares, delusions, hallucinations and flashbacks.
Behavioural and cognitive problems	Loss of memory, attention deficits, sequencing problems, deficits in organisational skills, confusion, apathy, disinhibition, compromised insight.
Other psychological or psychosocial problems	Low-self-esteem, poor or low self-image and/or body image issues, relationship difficulties, including those with the family and/or carer.

1.2 Care pathway



Key principle of care

To ensure continuity of care, healthcare professional(s) with the appropriate competencies should coordinate the patient's rehabilitation care pathway. Key elements of the coordination are as follows.

- Ensure the short- and medium-term rehabilitation goals are reviewed, agreed and updated throughout the patient's rehabilitation care pathway.
- Ensure the delivery of the structured and supported self-directed rehabilitation manual, when applicable.
- Liaise with primary/community care for the functional reassessment at 2-3 months after critical care discharge.
- Ensure information, including documentation, is communicated as appropriate to any other healthcare settings.
- Give patients the contact details of the healthcare professional(s) on discharge from critical care, and again on discharge from hospital.

Information and support

During the critical care stay, give information about:

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

Before discharge from critical care or as soon as possible after being discharged from critical care, give information about:

- the rehabilitation care pathway and, if applicable, emphasise the information about possible physical and non-physical problems
- the differences between critical care and ward-based care and the transfer of clinical responsibility to a different medical team
- sleeping problems, nightmares and hallucinations and the readjustment to ward-based care, if applicable.

Before discharge to home or community, give information about:

- the patient's physical recovery (based on the goals set if applicable) and how to manage activities of daily living
- diet and any other continuing treatments
- driving, returning to work, housing and benefits (if applicable); also local support services
- general guidance for the family/carer on what to expect and how to support the patient at home.

Give the patient their own copy of the critical care discharge summary.

1.3 Introduction

1.3.1 Critical illness: rehabilitation after a period of critical illness

More than 110,000 people are admitted into critical care units in England and Wales each year (estimated from the UK Intensive Care National Audit and Research Centre [ICNARC] Case Mix Programme [CMP] Summary Statistics); most 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) 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 during critical care and after discharge from critical care may help to improve patient outcomes. Such strategies may also reduce the length of stay in critical care and hospital stay after discharge from critical care, minimise hospital readmission rates and reduce 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 the 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 after 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 currently lacks 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 the general adult 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 recommending screening and/or assessment and appropriate rehabilitation strategies throughout the patient's rehabilitation care pathway. Key principles of care and information and the support needs of patients and their families and/or 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 83) 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 after a period of critical illness. The responsibility for coordinating rehabilitation lies at organisation level: rehabilitation for general critical care adult patients occurs along a patient pathway that crosses traditional medical team and ward boundaries and continues in community settings. Rehabilitation for general critical care adult

patients should be delivered by appropriate members of a multidisciplinary team (for example the ward staff; primary care team with other members joining intermittently, such as rehabilitation specialists, therapists, psychologists and social workers). Secondary care trusts may choose to configure their services in various ways, depending on existing services. Critical care teams do not generally have all the skills or infrastructure needed to deliver or coordinate rehabilitation throughout the patient's care pathway – and that is not the intended outcome of this guideline.

This is the full version of the guideline. It is available from www.nice.org.uk/CG83. 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/CG83

1.3.4 Developing the guideline recommendations

NICE has produced this guideline based on the best-available evidence, which was presented to a multidisciplinary group of healthcare professionals, patient representatives and carer representatives. The group used its clinical expertise and experience to draft recommendations based on this evidence. It is acknowledged that for rehabilitation after a period of critical care there is a limited evidence base. In some areas there was strong evidence but in other areas the evidence base was weaker or absent. It should be noted that there are many areas of healthcare where there is little or no research-based evidence. Where there is no research-based evidence, standard practice is to use the consensus opinion of the group developing the guideline on what constitutes good practice as the basis for guideline recommendations.

For each clinical question the GDG was presented with a summary of the clinical evidence and, where appropriate, the economic evidence from the studies that were reviewed and appraised. For areas where there was no evidence, the GDG agreed recommendations through informal consensus based on GDG members' experience in the field and their experience in other, related fields such as neurorehabilitation, cardiac rehabilitation and stroke rehabilitation. The link between the evidence and each recommendation is

made explicit in the accompanying ‘Evidence to recommendations’ sections. These sections set out the judgements that the GDG made in drafting the recommendations.

The GDG agreed the following definition of rehabilitation: ‘an active process to restore personal physical, mental and social capabilities and full autonomy’. If full recovery is not possible, the person’s optimal physical, mental and social potential should be aimed for. Rehabilitation can be delivered by a multidisciplinary team of healthcare professionals. This will include healthcare professionals with knowledge and skills in: critical care, rehabilitation medicine, physiotherapy, occupational therapy, clinical psychology, speech and language therapy, nutritional management and pain management.

2 Evidence review and recommendations

2.1 Screening and assessment tools

2.1.1 Overview

Patients admitted to critical care may experience physical and non-physical morbidity that affects their quality of life after discharge (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 et al. 1995; Haines 1974; Nava 1998). The duration of critical care stay is also associated with the degree of mobility problems (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. It 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 and communication 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% and 83% of patients intubated for longer than 48 hours (Leder et al. 1998; Tolep et al. 1996).

Non-physical morbidity

In addition to any physical morbidity, treatment in critical care may also be 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 (PTS)-related symptoms (Scragg et al. 2001; Sukantarat et al. 2007). As well as psychological problems, a significant percentage of critically ill patients experience cognitive dysfunction, which affects their quality of life and overall daily functioning in the longer term (Gordon et al. 2004). Substantial cognitive under-performance, including difficulties with problem-solving and poor memory, is a common occurrence during the first year after a critical illness (Jones et al. 2006; Sukantarat et al. 2005). These longer term cognitive impairments have also been shown to be associated with delirium because of the multiple physiological and pharmacologic stressors that affect the central nervous system during critical illness (Hopkins and Jackson 2006).

Screening and/or assessment of physical and non-physical morbidity

Despite the prevalence of physical and non-physical morbidity after critical care, it is frequently unrecognised and, even when identified, may not be appropriately assessed or managed. Comprehensive screening and assessment of the rehabilitation needs of critical care patients using an appropriate tool at appropriate points on the patient's care pathway has therefore been proposed as a necessary and integral part of continuing care (Hewitt 2002). It is therefore necessary to determine the effectiveness and cost effectiveness of any screening and/or assessment tools for rehabilitation needs used in this patient population and this question is addressed in the following evidence review.

Evidence review

Summary

We identified one study (Collen et al. 1991) on the clinical/test utility of an assessment tool for physical morbidity. No studies were identified on screening physical morbidity. We identified 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 screening tools for non-physical morbidity and one study on assessing cognitive dysfunction (Beauchamp et al. 2001). No studies were identified for screening and/or assessing swallowing and communication problems, and no specific

studies were identified on the optimal time to screen for and/or assess physical and non-physical morbidity. However, one study (Twigg et al. 2008) on screening for non-physical morbidity (post-traumatic stress disorder [PTSD]) reported an analysis of the optimal time to screen for acute PTSD. All seven included studies were appraised individually using the QUADAS (Quality Assessment of Studies of Diagnostic Accuracy) checklist (NICE guidelines manual 2009, appendix G; www.nice.org.uk/guidelinesmanual). For the appraisals of these studies, and a flowchart of the excluded studies, see the evidence tables and narrative summary in appendix 4.

Overall, the evidence was of mixed quality. Three out of the seven included studies (Beauchamp et al. 2001; Collen 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 '–').

Physical morbidity

One low-quality cohort study on an assessment tool for physical functional status was included (Collen et al. 1991). This cohort study was based on a rehabilitation population (patients who had a head injury, stroke or neurosurgery) in a single rehabilitation centre in the UK. This study needs cautious interpretation as it 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 shows 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) answers: scores range from 0 to 15.

Concurrent validity and inter-rater 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 $r = 0.91$ ($p < 0.01$).

Non-physical morbidity

(a) PTS symptoms

Two good-quality studies on screening tools for PTSD were included. One was a cohort study in the UK using the UK-PTSS-14 (UK PTS Syndrome 14-questions inventory) (Twigg et al. 2008) as a screening tool to identify patients at risk of suffering PTSD in ICUs. The UK-PTSS-14 is a 14-item self-report screening tool; each item is rated 1 (never) to 7 (always) with a total score ranging from 14 to 98. The Post-traumatic 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 three timepoints (4–14 days, 2 months and 3 months after ICU discharge). The PDS was only administered at 3 months after ICU discharge.

Concurrent validity, predictive validity and internal reliability of the UK-PTSS-14:

The internal reliability (Cronbach's α) of the UK-PTSS-14 was satisfactory (based on the rule of thumb: $\alpha > 0.70$ considered as satisfactory) (Bland and Altman 1997) with at 4–14 days: $\alpha = 0.89$; at 2 months: $\alpha = 0.86$ and at 3 months: $\alpha = 0.84$. 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:

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

After receiver operating characteristic (ROC) analysis, timepoint two (at 2 months after ICU discharge) had the highest area under the curve (AUC) index: 95% (95% CI, 84% to 99%) with a cut-off point of 45. The sensitivity

was 86% (95% CI, 42.2% to 97.6%) and the specificity was 97% (95% CI, 85.8% to 99.5%). The UK-PTSS-14 was only validated in this 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 a screening tool for PTSD was a cohort study from Germany (Stoll et al. 1999). The study population was adult ICU patients treated for ARDS. This study used the PTSS-10 (PTS Syndrome 10 questions inventory) as a screening tool for PTSD 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 of 1 (never) to 7 (always) with a total score ranging from 10 to 70. Structured clinical interview with two trained psychiatrists to diagnose PTSD according to DSM-IV criteria was used as reference standard for this study.

Test accuracy and internal reliability of the PTSS-10:

The internal reliability (Cronbach's α) of the PTSS-10 at 2 years after ICU discharge was satisfactory [based on the rule of thumb: $\alpha > 0.70$ considered as satisfactory (Bland and Altman 1997)] with $\alpha = 0.93$. 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% to 100%),
- specificity = 97.5% (95% CI, 91% to 100%),
- positive predictive value (PPV) = 91% (95% CI, 74% to 100%), and
- negative predictive value (NPV) = 93% (95% CI, 85% to 100%).

This study showed that the PTSS-10 has good test accuracy and internal reliability as a screening tool for chronic or delayed PTSD. However, the results only applied to ICU patients with ARDS.

(b) Depression and anxiety

Two good-quality studies on screening 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. 2002) as screening tools to identify patients at risk of depression and anxiety (STAI-X1 only for anxiety). The HADS is a 14-item scale with two subscales (the seven-item depression subscale [HADS-D] and the seven-item anxiety subscale [HADS-A]). 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 study. The study population was adult patients admitted to cardiac, respiratory and neurorehabilitation in an intensive rehabilitation centre in Italy. Patients were assessed in rehabilitation before any follow-up.

Test accuracy of the HADS-D:

The test accuracy 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%.

Test accuracy of the HADS-A and STAI-X1:

The test accuracy of the HADS-A in this study was reported as sensitivity = 72%, specificity = 84%, PPV = 60% and NPV = 90%. The test accuracy of the STAI-X1 was reported as sensitivity = 52%, specificity = 99%, PPV = 93% and NPV = 86%. Further analysis of ROC on STAI-X1 with an 80th percentile cut-off point instead of 90th percentile (psychologist clinical interview as reference standard) showed improved accuracy (sensitivity = 76%, specificity = 84%, PPV = 61%, NPV = 91% with AUC = 88% [95% CI, 80 to 95%]). Although it was assessed as of good quality, concerns were raised about the generalisability of this study: patients 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). The DASS is a 42-question scale (14 for each of 3 subscales: depression, anxiety and 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 needing 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.

Concurrent validity, criterion validity and internal reliability of the DASS in comparison with the 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, 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: $\rho = 0.734$, $p < 0.0001$; and
- DASS anxiety/HADS-A: $\rho = 0.666$, $p < 0.0001$.

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

- DASS depression/HADS-D: $\rho = 0.781$, $p < 0.0001$; and
- DASS anxiety/HADS-A: $\rho = 0.767$, $p < 0.0001$.

The criterion validity (measured using a Bland-Altman plot) of DASS was also reported as:

- DASS depression/HADS-D: r = 0.93, p < 0.000;1 and
- DASS anxiety/HADS-A: r = 0.88, p < 0.0001.

This study did not show 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 QUADAS checklist) on the Faces Anxiety Scale (FAS) as a screening tool for anxiety alone (McKinley and Madronio 2008). The FAS is a single-item scale with five 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 11cm by 24cm 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 ventilation.

Criterion validity of the FAS in relation to the SAI:

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

This study needs cautious interpretation as its aim 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.

(c) Cognitive dysfunction

One low-quality study (assessed as level '–' on the QUADAS checklist) on assessment tools for cognitive dysfunction was identified. This low-quality study was a quasi-experimental study (Beauchamp et al. 2001) assessing 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 cardiothoracic surgery ICU in the USA. There was no information on patients' characteristics and inclusion/exclusion criteria to the study. Both the Rancho scale and NICE are neurocognitive assessment tools to document patient's level of consciousness and level of cognitive function of patients (carried out by critical care nurses through observation). The Rancho scale is a non-verbal eight-level scale ranging from 1 (unresponsive) to 8 (orientated) while the NICE (derived from the Rancho scale) is a non-verbal nine-level scale ranging from 0 (absent brainstem reflexes) to 8 (orientated). There was no reference standard for this study. The inter-rater reliability for the Rancho scale was $\rho = 0.91$ while the inter-rater reliability for the NICE was $\rho = 0.94$.

This study needs cautious interpretation because of the study design (no reference standard) and the limited data (such as the limited analysis and lack of information on the study population).

In addition to studies on screening and/or assessment tools for cognitive dysfunction, we also identified background studies that proposed an association between delirium and longer-term adverse cognitive outcomes. Studies of an association between delirium in patients without dementia and

adverse cognitive outcomes have generally been carried out in non-critical care populations although data are likely to apply to critical care cohorts. For example, Francis and Kapoor's 1992 study (Francis and Kapoor 1992) showed that general hospitalised medical patients without dementia but with delirium had a significant decline in cognitive function compared with controls without delirium at 2-year follow-up. Dolan et al.'s study (Dolan et al. 2001) also suggested that patients having surgery for hip replacement who had delirium were more likely to have cognitive impairments at 2-year follow-up. Finally, in McCusker et al.'s study (McCusker et al. 2001), the results also showed that medical patients with delirium had lower MMSE scores at 1-year follow-up compared with controls.

(d) Delirium

Current data show that delirium may be the most common neuropsychiatric condition not only in general medical populations but also in up to 80% of critically ill patients (Ely et al. 2001a; Ely et al. 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 6-month follow-up. The patients in this study had a substantially younger mean age (53.2 years) than in other studies cited above. Since screening and interventions for critical care patients with delirium will be covered in detail in the NICE clinical guideline 'Delirium: diagnosis, prevention and management of delirium' (to be published in 2010), no evidence statements or recommendations are included in this guideline.

Evidence statements for screening and assessment tools

No evidence was found on the effectiveness of screening or assessment tools in improving the health outcomes of adults who have received critical care.

Evidence statements for physical morbidity

Screening:

- *There was no evidence on the use of validated tools to screen for physical morbidity in a UK general adult critical care population.*

- *There was no evidence on the use of validated tools to screen for swallowing and communication problems in a UK general adult critical care population.*

Assessment:

- *There was no evidence on the use of validated tools to assess physical morbidity in a UK general adult critical care population.*
- *There was no evidence on the use of validated tools to assess swallowing and communication difficulties in a UK general adult critical care population.*
- *The RMI showed good inter-rater reliability and concurrent validity for assessing UK adult neurorehabilitation patients at risk of physical functional impairment. This small study* was *assessed as of low quality.*

Optimal timing:

- *There was no evidence on optimal timing for screening and/or assessing physical morbidity, swallowing and communication in a UK general adult critical care population.*

Evidence statements for non-physical morbidity

(a) PTS symptoms

Screening:

- *The UK-PTSS-14 showed good concurrent validity, predictive validity and internal reliability for screening acute PTSD in a UK general adult critical care population. This was assessed as a good-quality study.*
- *The PTSS-10 showed good test accuracy and internal reliability for screening chronic or delayed-onset PTSD in critical care adult patients in Germany. This was assessed as a good-quality study.*

Assessment:

- *There was no evidence on the use of validated tools to assess symptoms of PTS in a UK general adult critical care population.*

Optimal timing:

- The use of the UK-PTSS-14 showed that the optimal timing to screen for the presence of acute PTSD was 2 months after discharge from critical care. This was assessed as a good-quality study.

(b) Depression and anxiety

Screening:

- *The DASS showed good concurrent validity, criterion validity and internal reliability for screening depression and anxiety in a UK general adult critical care population. However, the DASS consists of large number of questions. This was assessed as a good-quality study.*
- *The HADS showed good test accuracy for screening depression and anxiety in adult critical care patients in Italy. This was assessed as a good-quality study.*
- *The STAI-X1 showed good test accuracy for screening anxiety in adult critical care patients in Italy. This was assessed as a good-quality study.*
- *The FAS showed good criterion validity for screening anxiety in adult critical care inpatients in Australia. This was assessed as a low-quality study.*

Assessment:

- *There was no evidence on the use of validated tools to assess depression and anxiety in a UK general adult critical care population.*

Optimal timing:

- *There was no evidence on optimal timing for screening and/or assessing depression and anxiety in a UK general adult critical care population.*

(c) Cognitive dysfunction

Screening:

- *There was no evidence on the use of validated tools to screen cognitive dysfunction in a UK general adult critical care population.*

Assessment:

- *There was no evidence on the use of validated tools to assess cognitive dysfunction in a UK general adult critical care population.*

- *The Rancho Scale and NICE showed good inter-rater reliability for assessing the level of consciousness and gross level of cognitive function in US adult cardiothoracic patients. This was assessed as a low-quality study.*

Optimal timing:

- *There was no evidence on optimal timing for screening and/or assessing cognitive dysfunction in a UK general adult critical care population.*

Evidence to recommendations on screening and/or assessment tools for physical and non-physical morbidity

Physical morbidity:

Because of a lack of good-quality evidence for screening and/or assessment tools for physical morbidity (including swallowing and communication) in a general critical care population, the GDG were not able to make recommendations on the use of specific screening or assessment tools. However, the lack of validated tools does not rule out a practitioner's clinical assessment.

Non-physical morbidity:

The GDG were not able to make recommendations on the use of specific screening or assessment tools for non-physical morbidity because of limited good-quality evidence specific to a UK general adult critical care population, and for the following reasons.

- Although evidence for the UK-PTSS-14 showed it has good accuracy at 2 months after ICU discharge, the GDG considered that the use of a formal 14-item tool contradicts recommendations from 'Post-traumatic stress disorder (PTSD)' (NICE clinical guideline 26), which stated that for initial screening and recognition of PTSD, healthcare practitioners should question patients in a sensitive manner and should consider asking specific questions about symptoms such as flashback, nightmares and hyperarousal.
- DASS: the GDG considered that it lacks practicality because of the large number of questions (42 questions in total).

Although there was a lack of evidence on optimal timing, the GDG's consensus view was that:

- a general critical care patient's rehabilitation pathway should consist of five key stages: during the critical care stay; before discharge from critical care; during ward-based care; before discharge to home or community care; and 2–3 months after discharge from critical care.
- it is good clinical practice to perform clinical assessments of physical and non-physical morbidity at different stages of the patient's rehabilitation care pathway and to continually review and update their rehabilitation plan to ensure that patients who are at risk of physical morbidity are identified promptly.
- a short clinical assessment should be carried out as an entry point for at-risk patients to enter the rehabilitation care pathway; the GDG consensus on example findings from the short clinical assessment that may indicate the patient is at risk are shown in table 1.

Patients' rehabilitation care pathway

i) During the critical care stay

The GDG considered that clinical assessments to identify physical and non-physical morbidity and goal setting should be undertaken as early as possible during the critical care stay. This was based on GDG consensus that early identification, treatment and rehabilitation during critical care could reduce further rehabilitation needs.

ii) Before discharge from critical care

The GDG considered that a clinical reassessment ought to be carried out before the patient is discharged to ward-based care to ensure that:

- physical morbidity not previously identified during the patient's critical care stay is identified before discharge
- patients who are likely to be at a higher risk of developing non-physical morbidity (for example, patients with psychiatric history and previous experience of traumatic events) are the subject of a comprehensive assessment based on risk factors such as pre-existing psychological or

psychiatric distress, and those identified in the PTSD guideline (NICE clinical guideline 26)

- rehabilitation initiated during the critical care stay is continued and transferred appropriately when the patient is discharged to general ward-based care.

iii) Before discharge to home or community care

The GDG considered that, to prepare patients for their return home, another clinical assessment (functional assessment) needs to be in place to assess the patient's capacity and the help they needed to undertake daily activities. The physical and non-physical dimensions that are included in the functional assessment (see recommendation 1.1.8) came from GDG consensus.

iv) 2–3 months after discharge from critical care

Although there was evidence showing that the optimal timing for screening critical care patients at risk of developing acute PTSD is 2 months after critical care discharge (Twigg et al. 2008), the GDG considered that 2–3 months would be less restrictive and more practical and that the same interval should also apply to other non-physical morbidity and physical morbidity. The GDG considered that this reassessment should:

- include physical and non-physical dimensions from recommendation 1.1.8
- take place through face-to-face interviews to optimise the likelihood of identifying non-physical morbidity.

v) Key principle of care

The GDG acknowledged that a patient's rehabilitation care pathway involves different healthcare professional teams from secondary and primary care assessing patients' physical and non-physical morbidity and their rehabilitation (as outlined in section 1.3.3 – 'Using this guideline'). Because of this, careful coordination by appropriately trained healthcare professional(s) throughout the patient's rehabilitation care pathway is crucial to ensure continuity of care.

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 overall identification is more accurate 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 in the economic analysis along with outcomes for patients who may have false-positive or false-negative results.

Randomised controlled trials (RCTs) of the screening/assessments' ability to improve long-term outcomes are needed. 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 the cost effectiveness of these interventions is considered further in sections 2.2.5 and 2.2.6.

Recommendations

Key principle of care

Recommendation 1.1.1

To ensure continuity of care, healthcare professional(s) with the appropriate competencies[6] should coordinate the patient's rehabilitation care pathway. Key elements of the coordination are as follows.

- Ensure the short-term and medium-term rehabilitation goals are reviewed, agreed and updated throughout the patient's rehabilitation care pathway.
- Ensure the delivery of the structured and supported self-directed rehabilitation manual, when applicable.
- Liaise with primary/community care for the functional reassessment at 2–3 months after the patient's discharge from critical care.
- Ensure information, including documentation, is communicated between hospitals and to other hospital-based or community rehabilitation services and primary care services.
- Give patients the contact details of the healthcare professional(s) on discharge from critical care, and again on discharge from hospital.

See the NICE guideline on patient experience in adult NHS services.

During the critical care stay

Recommendation 1.1.2

During the patient's critical care stay and as early as clinically possible, perform a short clinical assessment to determine the patient's risk of developing physical and non-physical morbidity

[6] 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).

(see table 1).

Recommendation 1.1.3

For patients at risk of physical and non-physical morbidity, perform a comprehensive clinical assessment to identify their current rehabilitation needs. This should include assessments by healthcare professionals experienced in critical care and rehabilitation.

Recommendation 1.1.4

For patients at risk, agree short-term and medium-term rehabilitation goals, based on the comprehensive clinical assessment. The patient's family and/or carer should also be involved[7].

Recommendation 1.1.5

The comprehensive clinical assessment and the rehabilitation goals should be collated and documented in the patient's clinical records.

Before discharge from critical care

Recommendation 1.1.8

For patients who were previously identified as being at low risk, perform a short clinical assessment before their discharge from critical care to determine their risk of developing physical and non-physical morbidity (see table 1).

Recommendation 1.1.9

For patients at risk, and patients who started the individualised, structured rehabilitation programme in critical care, perform a

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

comprehensive clinical reassessment to identify current rehabilitation needs. The comprehensive reassessment should pay particular attention to:

- physical, sensory and communication problems (see table 2)
- underlying factors, such as pre-existing psychological or psychiatric distress
- symptoms that have developed during the critical care stay, such as delusions, intrusive memories, anxiety, panic episodes, nightmares, flashback episodes or depression (see the NICE guideline on the prevention, diagnosis and management of delirium).

Recommendation 1.1.10

For patients who were previously identified as being at risk during critical care, the outcomes of the comprehensive reassessment should inform the individualised, structured rehabilitation programme (recommendation 1.1.6).

Recommendation 1.1.11

For patients at risk, agree or review and update the rehabilitation goals, based on the comprehensive reassessment. The family and/or carer should also be involved, unless the patient disagrees.

Recommendation 1.1.12

Ensure that the transfer of patients and the formal structured 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

Recommendation 1.1.14

For patients who were previously identified as being at low risk

before discharge from critical care, perform a short clinical assessment to determine their risk of physical and non-physical morbidity (see table 1).

Recommendation 1.1.15

For patients at risk, perform a comprehensive clinical reassessment (see recommendation 1.1.9) to identify their current rehabilitation needs.

Before discharge to home or community care

Recommendation 1.1.20

Before discharging patients who were receiving the individualised structured rehabilitation programme during ward-based care (recommendation 1.1.15) (see the NICE guideline on the transition between inpatient hospital settings and community or care home settings for adults with social care needs):

- perform a functional assessment which, should include the following (also see table 2 for possible examples):

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

  Non-physical dimensions
  - anxiety
  - depression
  - post-traumatic stress-related symptoms
  - behavioural and cognitive problems
  - psychosocial 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 rehabilitation goals with the patient. The family and/or carer should be involved if the patient agrees.

2–3 months after discharge from critical care

Recommendation 1.1.23

Review patients with rehabilitation needs 2–3 months after their discharge from critical care. Carry out a functional reassessment of their health and social care needs, using the dimensions in recommendation 1.1.20. If appropriate, also enquire about sexual dysfunction.

Recommendation 1.1.24

The functional reassessment should be face to face in the community or in hospital, performed by an appropriately-skilled healthcare professional(s) who is familiar with the patient's critical care problems and rehabilitation care pathway.

Table 1 Examples from the short clinical assessment that may indicate the patient is at risk of developing physical and non-physical morbidity

Physical	Unable to get out of bed independently. Anticipated long duration of critical care stay. Obvious significant physical or neurological injury. Lack of cognitive functioning to continue exercise independently. Unable to self ventilate on 35% of oxygen or less. Presence of premorbid respiratory or mobility problems. Unable to mobilise independently over short distances.
Non-physical	Recurrent nightmares, particularly where patients report trying to stay awake to avoid nightmares. Intrusive memories of traumatic events which have occurred prior to admission (for example, road traffic accidents) or during their critical care stay (for example, delusion experiences or flashbacks). New and recurrent anxiety or panic attacks. Expressing the wish not to talk about their illness or changing the subject quickly off the topic.

Note: this list is not exhaustive and healthcare professionals should use their clinical judgement.

Table 2 Symptoms from the functional assessment that may indicate the presence of physical and non-physical morbidity

Physical dimensions	
Physical problems	Weakness, inability/partial ability to sit, rise to standing, or to walk, fatigue, pain, breathlessness, swallowing difficulties, incontinence, inability/partial ability 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, housing, benefits, employment and leisure needs.
Non-physical dimensions	
Anxiety, depression and PTS-related symptoms	New or recurrent somatic symptoms including palpitations, irritability and sweating; symptoms of derealisation and depersonalisation; avoidance behaviour; depressive symptoms including tearfulness and withdrawal; nightmares, delusions, hallucinations and flashbacks.
Behavioural and cognitive problems	Loss of memory, attention deficits, sequencing problems, deficits in organisational skills, confusion, apathy, disinhibition, compromised insight.
Other psychological or psychosocial problems	Low-self-esteem, poor or low self-image and/or body image issues, relationship difficulties, including those with the family and/or carer.

2.2 Rehabilitation strategies/programmes

Overview

Currently, rehabilitation strategies after a period of critical illness are not routinely provided, particularly after hospital discharge (Jones et al. 2003). Some critical care follow-up clinics provide multidisciplinary rehabilitation

strategies but their structure and configuration and the services they provide varied across the country (Griffiths et al. 2006) and there is currently a lack of evidence on their clinical effectiveness. There is therefore a need to conduct 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 after a period of critical illness.

Along with a new emphasis on rehabilitation after a period of critical illness, a new paradigm of early rehabilitation has replaced the old paradigm, which described rehabilitation as the third phase of medicine and implied that rehabilitation strategies should wait until the patient is medically and surgically stable (Rusk 1960). Several studies have shown that early rehabilitation, beginning at a point when the patient is physiologically stable and continuing through the critical care stay, might improve physical functioning and so contribute to an early discharge from critical care (Bailey et al. 2007). Identifying rehabilitation needs early and starting rehabilitation early can also reduce healthcare costs by reducing dependence, nursing care, length of stay and preventing disability (Evans et al. 1995; Indredavik et al. 1991; Johnston et al. 2003; Kramer et al. 1997). However, in a study by Thomsen et al (2008), not all critical care patients were rehabilitated early.

There is therefore also a need to conduct a systematic review of the effectiveness of early rehabilitation during critical care in reducing the subsequent risk of adult patients developing physical and non-physical morbidities after a period of critical illness.

Evidence review

Summary

We identified one RCT on the clinical effectiveness of rehabilitation strategies/programmes for UK general adult critical care patients who have developed physical and non-physical morbidity after their critical illness. See appendix 4 for an evaluation of the included study's outcomes using the modified GRADE (Grading of Recommendations Assessment, Development and Evaluation) methodology, as well as for the flowchart of excluded studies.

Rehabilitation strategies after critical care discharge

The included RCT (Jones et al. 2003) investigated the effectiveness of a 6-week supported self-help rehabilitation manual after critical care discharge. The patient population of this study was adult patients in three UK ICUs who had stayed for more than 48 hours and were being mechanically ventilated.

In this study, the rehabilitation strategy was a 6-week supported self-help rehabilitation manual plus 'usual care' at baseline. Control or 'usual care' in the study was defined as routine ICU follow-up, including three telephone follow-ups at the patient's home and ICU follow-up clinic appointments at 8 weeks and 6 months after ICU discharge. Rehabilitation started 1–2 weeks after 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; one telephone call a week for 3 weeks 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. Data were collected for analysis at baseline, 8-week follow-up and 6-month follow-up.

Table 3 Summary of GRADE profiles (Jones et al. 2003) (for full GRADE profiles, see appendix 4):

		Summary of findings				
		Number of patients		Effect		
Number of studies	Design	Intervention[a]	Control[b]	Relative (95% CI)	Absolute	Quality
Physical function[c] (at three timepoints: baseline, 8 weeks, 6 months after ICU discharge)						
1	RCT	58	44	ANOVA (at three timepoints interaction) F = 3.7, p = 0.006		Moderate
Physical function[c] (at 8 weeks after ICU discharge)						
1	RCT	63	51	Univariate ANOVA (at 8 weeks) F = 12.19, p < 0.0001		Moderate
Physical function[c] (at 6 months after ICU discharge)						
1	RCT	58	44	Univariate ANOVA (at 6 months) F = 14.4, p < 0.0001		Moderate
Depression[d] (at 8 weeks after ICU discharge)						
1	RCT	8/63 (12%)	13/51 (25%)	0.4981 (0.2239, 1.1082)	13%	Moderate
Depression[d] (at 6 months after ICU discharge)						
1	RCT	6/58 (10%)	5/44 (12%)	0.9103 (0.2696, 2.7908)	2%	Moderate
Anxiety[e] (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[f] (at 8 weeks after ICU discharge)						
1	RCT	63	51	One-way ANOVA (at 8 weeks) F = 5.24, p = 0.026		Moderate

[a] Intervention: 6-week self-help rehabilitation manual

[b] Control: usual care defined as: routine ICU follow-up included three telephone follow-ups at home; ICU follow-up clinic appointments at 8 weeks and 6 months.

[c] Physical function was measured by SF-36 (Short-form 36) physical function score.

[d] Depression was measured by HADS-D, with cut-off > 11 cases of depression.

[e] Anxiety was measured by HADS-A, with cut-off > 11 cases of anxiety.

[f] PTSD-related symptoms were measured using the Impact of Events Scale (IES).

Early rehabilitation during critical care

No studies were identified on how effective early rehabilitation is during critical care in reducing the risk of adult patients developing physical and non-physical morbidity after hospital discharge. Four studies were identified as supporting (indirect) evidence on the safety of early rehabilitation during critical care: two RCTs (Chiang et al. 2006; Galle et al. 2007) and two cohort

studies (Bailey et al. 2007) (see appendix 4). 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 6 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. One study (Galle et al. 2007) also showed that early exercise in a Belgium ICU (patients who were mechanically ventilated for more than five days) improved patients' physical function when they were discharged from hospital. Another study from the USA (Morris et al. 2008) also showed that early mobility therapy for ICU patients with acute respiratory failure was feasible, safe and reduced patients' ICU and hospital length of stay. Finally, 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 (for the evidence table see appendix 4).

Optimal timing for the delivery of rehabilitation

No studies were identified on the optimal time for initiating or delivering rehabilitation strategies to UK general adult critical care patients with physical and non-physical morbidity.

Evidence statements for the clinical effectiveness of rehabilitation strategies

Rehabilitation strategies after critical care discharge:

One study found that a 6-week supported self-help rehabilitation manual:

- *improved the recovery of patients' physical function 8 weeks and 6 months after ICU discharge*
- *did not improve patients' levels of depression 8 weeks and 6 months after ICU discharge*
- *did not improve patients' levels of anxiety 6 months after ICU discharge*
- *reduced patients' PTSD-related symptoms 8 weeks after ICU discharge but not at 6 months.*

This was assessed as moderate-quality evidence.

Early rehabilitation during critical care:

- *There was no evidence on the effectiveness of early rehabilitation during critical care in reducing subsequent risk of developing physical and non-physical morbidity after discharge from hospital.*

Optimal timing for the delivery of rehabilitation:

- *There was no evidence on the optimal timing for initiating or delivering rehabilitation strategies to UK general adult critical care patients with physical and non-physical morbidity.*

Evidence to recommendations on rehabilitation strategies/programmes

The GDG considered the limitations (as discussed in section 2.2.2) of the one included study (Jones et al. 2003) and agreed that the evidence could not be generalised to all general adult critical care patients at different stages of their rehabilitation care pathway. The GDG's consensus opinion is that it is good practice to provide individualised structured rehabilitation at each key stage of the patient's rehabilitation care pathway if recommendations on screening and/or assessment have been made. This is to ensure that patients who have been identified as at risk receive appropriate treatment.

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. However, the GDG discussed the supporting (indirect) evidence (as in section 2.2.2) on the feasibility and safety of early mobilisation, and agreed on the principle of early rehabilitation in critical care with agreed rehabilitation goals in an individualised, structured programme with measures to prevent avoidable morbidity.

ii) During ward-based care

Although Jones et al.'s (2003) study could not be generalised to all general adult critical care patients, the GDG agreed that the structured and supported self-directed rehabilitation manual used in the study could be part of the

patient's individualised structured rehabilitation programme based on clinical judgement and individual patients' needs.

iii) Before discharge to home or community care

The GDG agreed that there should be consensus recommendations on good practice to ensure continuity of care from hospital to home/community settings, including making sure: appropriate arrangements about their rehabilitation are made for patients; discharge documents are forwarded to all other appropriate services; and patients and their family or carers are aware of and understand all these arrangements.

iv) 2–3 months after discharge from critical care

As above, the GDG felt that consensus recommendations on good practice should be made to ensure continuity of care, including making referrals to appropriate rehabilitation or specialist services based on other NICE guidelines such as 'Depression (amended)' (NICE clinical guideline 23), 'Anxiety (amended)' (NICE clinical guideline 22) and 'Post-traumatic stress disorder (PTSD)' (NICE clinical guideline 26).

v) Key principle of care

The GDG agreed that the same rationales and principles as discussed in section 2.1.4 'Evidence to recommendations – v) Key principle of care' should also apply to the initiation and/or the delivery of the individualised structured rehabilitation programme.

Health economics

Published health economic literature

Given that identification and response should ideally be considered as an integrated decision problem, we carried out a systematic review of the literature to identify evidence on the cost effectiveness of 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 did not identify any cost-effectiveness studies on

screening/assessment tools that specifically examined the cost effectiveness of screening tools to identify rehabilitation needs or their optimal timing. In addition no studies were identified that specifically examined the cost effectiveness of rehabilitation as an intervention. Most of the studies identified were on quality of life and survival or were costing studies or review papers. None of these studies compared a rehabilitation intervention with standard care.

The PRACTICAL study is an ongoing RCT 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. 2007) indicates that resource use will be estimated for study participants based on patient questionnaires and a review of hospital notes. The EQ-5D questionnaire is being administered in this study, the results of which will be used to estimate quality-adjusted life years (QALYs). It is not known when the final results of this study will be reported.

The clinical systematic review of 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 considered by the guideline developers. A full review of this report was carried out and a data extraction table is in appendix 5.

The economic analysis described in the above report compared the cost effectiveness of introducing an information booklet on rehabilitation against usual care, when patients are discharged with no special information. The booklet was given to the intervention group after a 20-minute discussion with a dedicated nurse. The control group was discharged from hospital using the standard hospital protocol (the patient is given no additional information). Both groups received a follow-up telephone call at weeks 2, 4 and 6. The analysis was undertaken from an NHS and personal social services perspective and data were collected over 6 months. Although data were collected throughout

the trial period described in Jones et al. (2003), the economic analysis concentrated on the period from when patients were given the intervention until the 6-month follow-up. The authors did not carry out modelling to examine the result of lifetime extrapolation of costs and benefits.

All relevant effectiveness data collected in the trial were used in this study. However, while the economic evaluation reported that the EQ-5D instrument was used as part of the clinical trial, Jones et al. (Jones et al. 2003) make no mention of this tool, and present only SF-36 results. Utilities in the economic evaluation (Centre for Health Planning and Management 2001) 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 after discharge. It is not clear how the baseline assessment was made 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-month 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 for each patient from the appropriate social services department and information direct from patients at outpatient follow-up were 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)[8]. The differences in costs between the

[8] Adjusted for clarity from 2000 prices to 2006/7 prices by an inflation factor of 28% (www.pssru.ac.uk/pdf/uc/uc2007/uc2007.pdf).

intervention and control group were reported as not significant. No further statistical information on these data was reported.

Total QALYs were reported for the intervention and control groups at 6 months. Total QALYs appear to have been 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 (£1204). This estimate was calculated by using the total costs and total effectiveness for each group. However, in this case the incremental cost-effectiveness ratio (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 needed on how QALYs were calculated in order to assess the accuracy of the reported ICER. Sensitivity analysis was not carried out on the results so there is no quantitative information on 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 et al. 2006), only 30% of units surveyed in 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 (because of any possible therapeutic effect of the phone calls associated with the intervention group). Costs were appropriately applied, but this meant that the control group had better care compared with standard UK healthcare. It may also be the case that the cost of the intervention provided in addition to the follow-up clinic was marginal but it is unknown whether the intervention could be applied in a setting where no follow-up clinic is already in place. To

set up a dedicated follow-up clinic in order to implement a self-help manual would be more costly than implementing the self-help manual alone.

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 show a difference in economic outcomes.

De novo cost-effectiveness analysis

A lack of evidence, particularly on screening and assessment methods, meant that we could not carry out de novo economic analysis for this guideline.

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

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. We do not know what resource use is likely to be needed 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 because of inadequate RCT evidence on the effectiveness of rehabilitation interventions. No observational studies were identified in the clinical review.

Health economics evidence to recommendations

The GDG recognised the lack of evidence about the clinical and cost effectiveness of the interventions covered by this guideline. The GDG noted the lack 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 has a number of limitations. For example, the GDG recognised that standard care included follow-up visits at an ICU rehabilitation clinic, so the control arm could not be said to 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 cost effective. However, it was the GDG's view that the data were insufficient to show a difference between the two alternatives. Nevertheless, the benefits of the self-help manual were shown in the clinical trial. 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 patients as part of an individualised structured programme.

Recommendations

During the critical care stay

Recommendation 1.1.6

For patients at risk, start rehabilitation as early as clinically possible, based on the comprehensive clinical assessment and the rehabilitation goals. Rehabilitation should include:

- measures to prevent avoidable physical and non-physical morbidity, including a review of previous and current medication
- nutrition support, based on the recommendations in 'Nutrition support in adults' (NICE clinical guideline 32)
- an individualised, structured rehabilitation programme with frequent follow-up reviews. The details of the structured rehabilitation programme and the reviews should be collated and documented in the patient's clinical records.

During ward-based care

Recommendation 1.1.16

For patients at risk, offer an individualised, structured rehabilitation programme, based on the comprehensive clinical reassessment[9] and the agreed or updated rehabilitation goals set before the patient was discharged from critical care.

Recommendation 1.1.17

The individualised, structured rehabilitation programme should be developed and delivered by members of a multidisciplinary team, and should include appropriate referrals, if applicable.

Recommendation 1.1.18

Based on clinical judgement and the individual patient's

[9] Comprehensive reassessments apply to both those before discharge from critical care and during ward-based care.

rehabilitation needs, consider offering a structured and supported self-directed rehabilitation manual[10] for at least 6 weeks after discharge from critical care, as part of the individualised, structured rehabilitation programme.

Recommendation 1.1.19

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

Recommendation 1.1.21

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

- discharge arrangements, including appropriate referrals for the necessary ongoing care, are in place 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 and/or carer as appropriate, is aware of the discharge arrangements and understands them (see the NICE guideline on intermediate care including reablement).

2–3 months after discharge from critical care

Recommendation 1.1.25

Based on the functional reassessment.

[10] The structured and supported self-directed rehabilitation manual (based on Jones et al. 2003) should be coordinated by an appropriately skilled healthcare professional throughout its duration. The optimal time for starting the structured and supported self-directed rehabilitation manual should be based on individual patients' physical and cognitive capacity at different stages of their illness and recovery.

- 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 their rehabilitation goals, or
  - the patient has developed unanticipated physical and/or non-physical morbidity that was not previously identified.
- Give support if the patient is not recovering as quickly as they anticipated.
- If anxiety or depression is suspected, follow the stepped care models recommended in 'Anxiety' (NICE clinical guideline 22) and 'Depression' (NICE clinical guideline 23).
- If PTSD is suspected or the patient has significant symptoms of PTS, refer to 'Post-traumatic stress disorder (PTSD)' (NICE clinical guideline 26).

2.3 Information and support needs

Overview

Patients being treated in a critical care area are recovering from a serious illness and are dependent on the care provided by healthcare professionals and the support of their families/carers throughout their recovery. Research suggests that the care of a critically ill patient is not complete without some consideration of the psychological consequence(s) of the illness. 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, such as the inability to control or predict events (Jones and O'Donnell 1994); unmet informational and emotional needs (Benzer 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 1993; Sawdon et al. 1995; Stanton 1991), while others

have vivid recollections of their stay (Green 1996), and experience disturbing dreams, sleep deprivation and anxiety.

The government's 'National strategy for carers' (Department of Health 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 their physical and mental health. A study by Gillis (Gillis 1984) has shown that when patients were admitted to critical care, family members or carers can 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 1996), all of which could cause anxiety and depression (Young et al. 2005),or PTS-related symptoms (Jones et al. 2004).

Currently, some critical care units use patient diaries as a way to deliver information to both the patient and their families and/or carers. A number of observational studies have demonstrated that using patient diaries helped patients to understand their critical care stay (Backman and Walther 2001; Bergbom et al. 1999; Roulin et al. 2007). However, more clinical trials are needed in order to fully assess the clinical effectiveness of patient diaries.

Evidence review

Summary

We identified three studies that addressed information and support viewed as important by adult patients and their families/carers during, and after, a period of critical illness requiring critical care. 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 (www.healthtalkonline.org/other_conditions/intensive_care and www.healthtalkonline.org/other_conditions/intensive_care_experiences_of_family_friends). All four studies used a qualitative study design and were appraised individually using the NICE qualitative studies checklist (NICE Clinical Guidelines Manual 2009). The evidence was presented in evidence

tables and a narrative summary (see appendix 4). For the flowchart of excluded studies see appendix 4.

Overall, the evidence was of good quality. Two of the four included studies were graded as '++' based on the NICE qualitative studies checklist (DIPEx) and (Strahan and Brown 2005) and the other two included studies were graded as '+' (Combe 2005; McKinney and Deeny 2002; Paul et al. 2004).

Information and support needs

All four included studies were in the UK. The DIPEx critical care modules collected the experiences and views of critical care adult patients throughout their treatment journey, from admission to critical care through to recovery at home. A total of 40 adult patients and 38 families/carers were recruited in the study. Data were analysed and grouped under different topic summaries. DIPEx is a charity-run website aimed at patients, their carers, family and friends, doctors, nurses and other health professionals. Its 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, and 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. Researchers collect interviews until they are convinced that they have represented the main experiences and views of people within the UK. The study from Strahan and Brown (Strahan and Brown 2005) collected the experiences and views of 10 adult patients after transfer from critical care. The study focused on patients' experiences immediately after discharge to wards and their views on information and support needs perceived as important, before and after the transfer, to prevent stress or development of further psychological problems.

The other two studies from McKinney and Deeny (McKinney and Deeny 2002) and Paul et al. (Paul et al. 2004) focused on patients' experiences, views, and information needs upon transfer from critical care to ward-based care. McKinney and Deeny's study (McKinney and Deeny 2002) collected data from six adult critical care patients during the 48 hours after 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 and/or carers to construct an information booklet.

All results on patients' and families' carers' information needs from the four included studies were summarised using thematic analysis and presented in the table below (table 4). The results are grouped by key stages of the patient's care pathway.

Table 4 Summary of findings

During critical care	Study
Information at different stages of illness and recovery. The elements of information needs included: • basic information on the illness, the treatments and what had happened • information on weakness and muscle loss • information on likely hospital length of stay and recovery • having all the above information repeated again and again • information on equipment used • involvement of family/carers in sharing the information.	(DIPEx)
Before critical care discharge and during ward-based care	
1. Information on and a discussion from healthcare professionals about what happened in ICU and all possible related ICU syndromes. The elements of information and support needs included information on and reassurance about dreams and hallucination, and other elements, for example:	(DIPEx), (Strahan et al. 05)
• 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 the patient's care pathway.	(DIPEx)
• Information and support on setting goals for physical recovery. The elements of information and support needs included the patients' own critical illness and explanation on recovery.	(DIPEx) (Strahan et al. 05)
3. 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 (before transfer). The elements of the briefing included differences in:	(McKinney et al. 02)
• the physical environment	(McKinney et al. 02), (Paul et al. 04)
• staffing levels	(McKinney et al. 02), (Paul et al. 04)
• monitoring levels.	(McKinney et al. 02)
Before discharge to home/community care	
1. Information and discussion on discharge plan before hospital discharge. The elements of information and support needs included:	(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 they have not been given one at ICU discharge.	(DIPEx)
2. Support to prepare patients to go home. Elements of support needs included:	(Paul et al. 04)
• discussion on available support services	(Paul et al. 04)
• discussion on rehabilitation	(Paul et al. 04), (DIPEx)
• sources of further help.	(Paul et al. 04), (DIPEx)

Home or community care (recovering at home)	
1. Information on physical recovery and the impact on daily living	(DIPEx)
2. Information on and discussion of the emotional aspects of recovery: the elements of information discussed included:	(DIPEx)
• discussion on any non-physical morbidity	(DIPEx)
• information on referrals or other voluntary support group.	(DIPEx)

Evidence statements for information and support needs

During critical care stay, patients and their families/carers identified four important elements of information and support needs:

- *Information on the critical illness and treatments, equipment used, weakness and muscle loss.*
- *Information on the likely hospital length of stay and recovery.*
- *To have all the information repeated more than once.*
- *To share the information with families/carers.*

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 with both patients and their families and/or carers on transfer details 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 before 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 about physical recovery.*
- *Information on the impact on daily living.*
- *Information on non-physical morbidity.*
- *Information on the availability of and how to access other statutory and non-statutory supportive services such as charity support groups.*

Evidence to recommendations on information and support needs

The GDG considered that the qualitative evidence summarised above should form the basis for their recommendations in this area. The rationale for the additional recommendations not directly based on this evidence is presented below.

Patient's rehabilitation care pathway

i) During the critical care stay

The GDG considered that detailed information on physical problems and recovery is not appropriate at this stage as patients could be still very ill or even unconscious. Sharing information with their families and/or carers is important at this stage for the same reason unless the patient has the capacity to object.

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

The GDG considered that it was important to offer a structured handover from critical care to ward-based care as recommended in the 'Acutely ill patients in hospital' guideline (NICE clinical guideline 50).

iii) Before discharge to home or community care

The GDG considered that advice and information on how to manage activities of daily living is very important to prepare patients to recover at home, and that general guidance on carers' own needs, and what to expect regarding how to support the patient at home, should also be provided to the family and/or carer.

iv) 2–3 months after discharge from critical care

The GDG considered that information on statutory and non-statutory supportive services should be provided before hospital discharge.

Health economics

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

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

Recommendations

During the critical care stay

Recommendation 1.1.7

Give patients the following information during their critical care stay. Also give the information to their family and/or carer[11], unless the patient disagrees.

- Information about the patient's critical illness, interventions and treatments.
- Information about the equipment used during the patient's critical care stay.
- If applicable, information about any possible short-term and/or long-term physical and non-physical problems which may require rehabilitation.

Deliver all the above information more than once during the patient's critical care stay.

Before discharge from critical care

Recommendation 1.1.13

Give patients the following information before, or as soon as possible after, their discharge from critical care. Also give the information to their family and/or carer, unless the patient disagrees.

- 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, and staffing and monitoring levels.
- Information about the transfer of clinical responsibility to a

[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.

different medical team (this includes information about the formal structured handover of care recommended in ‘Acutely ill patients in hospital’ (NICE clinical guideline 50).

- If applicable, emphasise the information about possible short-term and/or long-term physical and non-physical problems that may require rehabilitation.
- If applicable, information about sleeping problems, nightmares and hallucinations and the readjustment to ward-based care.

Before discharge to home or community care

Recommendation 1.1.22

Give patients the following information before their discharge to home or community care. Also give the information to their family and/or carer, if the patient agrees.

- Information about their physical recovery, based on the goals set during ward-based care if applicable.
- If applicable, information about diet and any other continuing treatments.
- Information about how to manage activities of daily living including self-care and re-engaging with everyday life.
- If applicable, information about driving, returning to work, housing and benefits.
- Information about local statutory and non-statutory support services, such as support groups.
- General guidance, especially for the family and/or 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.
- Give the patient their own copy of the critical care discharge summary.

2.4 Research recommendations

- What is the most effective way of identifying patients at risk of critical illness-associated physical morbidity, psychological morbidity and cognitive dysfunction and how can the disease progress and response to interventions monitored?
- In patients at high risk, which therapeutic strategies are the most clinically and cost effective at reducing the prevalence and severity of critical illness-associated physical morbidity, psychological morbidity and cognitive dysfunction?
- In patients with established morbidity, which **specific** therapeutic strategies are the most clinically and cost effective at reducing the magnitude of critical illness-associated physical morbidity, psychological morbidity and cognitive dysfunction?
- For patients at high risk of critical illness-associated morbidity, what is the clinical effectiveness and cost effectiveness of organised critical care rehabilitation versus usual care on physical and psychological functioning, participation and quality of life?
- For those patients **not** identified as at high risk of critical illness-associated morbidity, what is the clinical effectiveness and cost effectiveness of organised critical care rehabilitation versus usual care on physical, psychological functioning, participation and quality of life?

3 Glossary, abbreviations and references

3.1 Glossary and abbreviations

3.1.1 Glossary

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

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.
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.
Negative predictive value The proportion of patients with negative test results who are correctly diagnosed.
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 Includes muscle loss, muscle weakness, joint pain, loss of bone, sensory problems, swallowing and communication problems.
Non-physical morbidity Include 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.
Qualitative research Research concerned with subjective outcomes relating to social, emotional and experiential phenomena in health and social care.
Quality-adjusted life year (QALY) The QALY is a single measure of health related quality of life that takes into account both the quantity and quality of life provided by the intervention.
Randomised controlled trial A comparative study in which participants are randomly allocated to intervention and control groups and followed up to examine differences in outcomes between the group.
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 versus (100% – 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 before 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).

3.1.2 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

3.1.3 References

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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 www.nice.org.uk/CG83

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) in 'The guidelines manual' (2009) (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 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 (GDG) 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. For details of the GDG members and the technical team, please see section 5.1.

4.2.3 Developing review questions

The third step in the development of the guidance was to refine the scope into a series of key clinical issues. The key clinical issues were developed by the Guideline Development Group with assistance from the Short Clinical Guidelines Technical Team. As necessary, the key clinical issues were refined into specific review questions by the project teams to aid literature searching, appraisal and synthesis. The full list of key clinical issues and review questions are shown in appendix 2.

The Guideline Development Group and Short Clinical Guidelines Technical Team also 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 2009' by NICE. 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 structured clinical questions developed from the guideline scope. The Technical Analyst had primary responsibility for reviewing the evidence but was supported by the Project Lead, Information Scientist and Health Economist.

Studies retrieved by the searches were first sifted by the Short Clinical Guidelines Technical Team using title and abstract. 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.

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 determined the validity of the results. These criteria

differed according to study type and were based on the checklists included in 'The guidelines manual 2009' by NICE (available from: www.nice.org.uk/guidelinesmanual). For the checklists that were used in this particular guideline see appendix 6.

4.2.7 Grading the evidence

Intervention studies

There are many different methods of assigning levels to the evidence and there has been considerable debate about what system is best. 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 NICE guidelines manual 2009. For the checklists see appendix 6.

Presenting intervention studies with modified GRADE

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. More information about GRADE and its use 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 and The NICE guidelines manual 2009). 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

Qualitative studies in this guideline were assessed using the checklist for qualitative studies (see appendix 6 and The NICE guidelines manual 2009). 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.

4.2.8 Evidence to recommendations

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 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. Most of the studies identified were concerned with the costing of intensive care or health-related quality of life or survival after a stay in intensive care. None of these studies compared a rehabilitation intervention with standard care.

A cost-effectiveness analysis was not possible because of insufficient clinical evidence.

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

4.2.10 Consultation

The draft of the full guideline was available on the website for consultation, and registered stakeholders were informed by NICE that the documents were available. Non-registered stakeholders could view the guideline on the NICE website.

4.2.11 Other national guidance

NICE has issued the following related guidance:

Stroke: the diagnosis and acute management of acute stroke and transient ischaemic attacks. NICE clinical guideline 68 (2008). Available from www.nice.org.uk/CG68

Head injury: triage, assessment, investigation and early management of head injury in infants, children and adults. NICE clinical guideline 56 (2007). Available from www.nice.org.uk/CG56

Acutely ill patients in hospital: recognition of and response to acute illness in adults in hospital (2007). Available from www.nice.org.uk/CG50

MI: secondary prevention: secondary prevention in primary and secondary care for patients following a myocardial infarction. NICE clinical guideline 48 (2007). Available from www.nice.org.uk/CG48

Depression (amended): management of depression in primary and secondary care. NICE clinical guideline 23 (2007). Available from www.nice.org.uk/CG23

Anxiety (amended): management of anxiety (panic disorder, with or without agoraphobia, and generalised anxiety disorder) in adults in primary, secondary and community care. NICE clinical guideline 22 (2007). Available from www.nice.org.uk/CG22

Dementia: supporting people with dementia and their carers in health and social care. NICE clinical guideline 42 (2006). Available from www.nice.org.uk/CG42

Nutrition support in adults: oral nutrition support, enteral tube feeding and parenteral nutrition. NICE clinical guideline 32 (2006). Available from www.nice.org.uk/CG32

Post-traumatic stress disorder (PTSD): the management of PTSD in adults and children in primary and secondary care. NICE clinical guideline 26 (2005). Available from www.nice.org.uk/CG26

NICE is developing the following guidance (details available from www.nice.org.uk):

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

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.

Stephen Brett (Chair) – Consultant in Intensive Care Medicine

Bipin Bhakta – Consultant Physician and Clinical Director of Specialist Rehabilitation Services

Nichola Chater – Consultant in Rehabilitation Medicine and Honorary Clinical Tutor

Brian Cuthbertson – Professor of Critical Care

Jane Eddleston – Consultant in Intensive Care

Melanie Gager – Sister, Critical Care Follow Up

Peter Gibb – Patient/carer member

Karen Hoffman – Clinical Specialist Occupational Therapist - Neurosciences

Christina Jones – Nurse Consultant in Critical Care Follow Up

Amanda Lurie – Consultant Clinical Psychologist

David McWilliams – Senior Specialist Physiotherapist

Dawn Roe – Patient/carer member

Amanda Thomas – Clinical Specialist Physiotherapist

Carl Waldmann – Consultant in Intensive Care

Barry Williams – Patient/carer member

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 – Consultant Physician and Honorary Senior Lecturer in Respiratory and Critical Care Medicine

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.

Lynda Ayiku – Information Specialist

Emma Banks – Coordinator

Kathryn Chamberlain – Project Manager

Nicole Elliott – Commissioning Manager

Ruth McAllister – Health Economist

Dr Tim Stokes – Guideline Lead and Associate Director

Toni Tan – Technical Analyst

5.1.2 Guideline Review Panel

Professor Mike Drummond – Chair Director, Centre for Health Economics, University of York

Dr Graham Archard – General Practitioner, Dorset

Ms Catherine Arkley – Lay memberMs Karen Cowley – Practice Development Nurse, York

Dr David Gillen – Medical Director, Wyeth Pharmaceutical

5.1.3 List of stakeholders

Arrhythmia Alliance

Association for Chartered Physiotherapists in Respiratory Care

Association of Catholic Nurses of England and Wales

Association of the British Pharmaceuticals Industry (ABPI)

Arjo Huntleigh

Atrial Fibrillation Association

Barnsley Hospital NHS Foundation Trust

Barts and The London NHS Foundation Trust

Bedfordshire PCT

Birmingham & the Black Country Critical Care Network

Boehringer Ingelheim Ltd

Bournemouth and Poole PCT

Bradford Teaching Hospitals NHS Foundation Trust

Brighton and Sussex University Hospitals NHS Trust

British Association for Counselling & Psychotherapy

British Association of Cardiac Rehabilitation

British Association of Critical Care Nurses

British Cardiovascular Society

British Dietetic Society

British Geriatrics Society

British Heart Foundation

British National Formulary (BNF)

British Orthopaedic Association

British Pain Society

British Psychological Society

British Society of Rehabilitation Medicine

British Thoracic Society

BUPA

Cambridge University Hospitals NHS Foundation Trust

CASPE Research

Central Manchester and Manchester Children's University Hospital

Chartered Society of Physiotherapy (CSP)

Chelsea & Westminster Acute Trust

Cheshire PCT

City Hospitals Sunderland NHS Trust

College of Occupational Therapists

Coloplast Ltd

Commission for Social Care Inspection

Connecting for Health

Critical Care Network, Northern Ireland (CCaNNI)

Coventry and Warwickshire Cardiac Network

Department for Communities and Local Government

Department of Health

Department of Health, Social Security and Public Safety of Northern Ireland

Derbyshire Mental Health Services NHS Trust

East & North & West Hertfordshire PCTs

East Kent Hospitals NHS Trust

Faculty of Occupational Medicine

GlaxoSmithKline UK

Gloucestershire Hospitals NHS Trust

Guy's and St Thomas' NHS Foundation Trust

Harrogate and District NHS Foundation Trust

Health Commission Wales

Healthcare Commission

Hertfordshire Partnership NHS Trust

Herts & Beds Critical Care Network

Hill-Rom

ICUsteps

Institute of Biomedical Science

Intensive Care Aftercare Network

Intensive Care National Audit & Research Centre (ICNARC)

Intensive Care Society

Intercollegiate Board for Training in Intensive Care Medicine

Ipswich Hospital NHS Trust

Kirklees PCT

Lancashire Teaching Hospitals Acute Trust

Leeds PCT

Long-term Conditions Alliance

Luton & Dunstable Hospital NHS Foundation Trust

Medicines and Healthcare Products Regulatory Agency

Medway NHS Trust

Mid Trent Critical Care Network

Milton Keynes PCT

MRSA Action UK

National Outreach Forum (NOrF)

National Patient Safety Agency

National Public Health Service - Wales

National Spinal Injuries Centre

National Treatment Agency for Substance Misuse

NCCHTA

NHS Clinical Knowledge Summaries Service (SCHIN)

NHS Plus

NHS Purchasing & Supply Agency

NHS Quality Improvement Scotland

NHS Sheffield

Norfolk, Suffolk and Cambridgeshire Critical Care Network

North Bristol NHS Trust

North East & Cumbria Critical Care Network

North Trent Critical Care Network

North West London Critical Care Network

North Yorkshire and York PCT

Northampton General Hospital NHS Trust

Northumbria Healthcare NHS Foundation Trust

Nottingham University Hospitals NHS Trust

Nutricia Clinical Care

Oklahoma State University

Oxford Radcliffe Hospitals NHS Trust

Paediatric Intensive Care Society

Patient Liaison Group

Pennine Acute Hospitals NHS Trust

PERIGON Healthcare Ltd

Pernicious Anaemia Society

Plymouth PCT

Plymouth Teaching PCT

Renal Association

Royal Brompton & Harefield NHS Trust

Royal College of General Practitioners

Royal College of Nursing

Royal College of Paediatrics and Child Health

Royal College of Pathologists

Royal College of Physicians of London

Royal College of Psychiatrists

Royal College of Radiologists

Royal College of Speech and Language Therapists

Royal Liverpool and Broadgreen NHS Trust

Royal Society of Medicine

SACAR

Sandwell PCT

Scottish Intercollegiate Guidelines Network (SIGN)

Sheffield PCT

Sheffield Teaching Hospitals NHS Foundation Trust

Sherwood Forest Hospitals NHS Foundation Trust

Social Care Institute for Excellence (SCIE)

Society of British Neurological Surgeons

South East Wales Critical Care Network

South Manchester University Hospitals NHS Trust

South Tees Hospitals NHS Trust

South West London Cardiac & Stroke Network

Southport & Ormskirk Hospital NHS Trust

Surrey Wide Critical Care Network

Sussex Critical Care Network

Tees Valley & South Durham Critical Care Network

UKCPA – Infection Management Group

United Kingdom Clinical Pharmacy Association

University Hospital Birmingham NHS Foundation Trust

Walsall Hospital NHS Trust

Walton Centre for Neurology & Neurosurgery

Welsh Assembly Government

Welsh Scientific Advisory Committee (WSAC)

Western Health and Social Care Trust

York NHS Foundation Trust

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: National Institute for Health and Clinical Excellence (2009) Rehabilitation after critical illness. London: National Institute for Health and Clinical Excellence. Available from: www.nice.org.uk/CG83

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).